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Early palliative care for people with advanced illnesses:  
research into practice

Kirsty Jean Boyd



THE UNIVERSITY  
*of* EDINBURGH

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## Declaration

I declare that I have written this thesis, that I have made a substantial contribution, clearly indicated, to each of the published papers, and that this work has not been submitted for any other degree or professional qualification. My published papers are reproduced with permission.



Kirsty Jean Boyd

Edinburgh  
November 2015

## Abstract

Identifying people with advanced illnesses whose health is deteriorating, assessing their needs and planning care proactively with them are healthcare priorities given the demographic trend of ageing populations in the UK and internationally. Over the past 10 years (2004-2014), I have led a series of research studies that have made an important academic contribution to improving palliative care services for patients with heart disease and advanced multimorbidity.

My first paper reported secondary analysis of data generated from a qualitative study of the illness and care experiences of patients with advanced heart failure. This work used innovative, qualitative research methods to explore and understand patient, carer and health professional perspectives over time. My second study then evaluated whether health and social care services were configured and delivered in response to the needs of people with heart failure and their families. This led me to recommend an anticipatory care framework which integrated a palliative care approach with other aspects of treatment and care. Around this time, advance care planning (planning ahead to facilitate end-of-life care aligned with people's goals and preferences) was being strongly advocated by NHS health policy makers despite limited research in the UK. For my third study, I evaluated an evidence-based, educational intervention for general practitioners while also exploring barriers and facilitators to advance care planning in primary care for patients with cancer or other advanced conditions.

It was becoming increasingly clear that failure to identify people with deteriorating health and a high risk of dying in a timely way was a major barrier to more effective palliative care. The problem was greatest for patients with non-malignant conditions whose illness trajectory is much less easy to predict than in cancer populations. I therefore started to research and develop a new clinical tool designed to prompt early, proactive patient identification in routine clinical practice – the Supportive and Palliative Care Indicators Tool (SPICT). My fourth research paper reported an evaluation of the SPICT in a mixed-methods study in a large tertiary care hospital. The SPICT was then used to identify people with multimorbidity for my fifth study, a longitudinal exploration of patient and carer experiences of hospital admission and ongoing community care.

In my final paper, I drew on my previous research and combined this with well-developed approaches to timely identification and effective communication. I described the design of a successful pilot randomised trial of future care planning with people who had advanced heart disease and their carers.

This thesis presents a critical review of these six research studies setting them in context and demonstrating the impact they have had in ensuring that high quality research evidence informs current and future developments in palliative care policy and clinical practice.

## Lay summary

The number of older people with advanced illnesses in the UK and other countries is increasing. It is important to identify these people and find out what help and support they need so that we can make sure their treatment and care is as good as it can be when their health is deteriorating, and then when they are dying. In these six papers, I have described research work that aimed to help improve supportive and palliative care for people with advanced heart disease or multiple advanced, progressive illnesses.

My first paper described a research study where people with advanced heart failure and the family members who cared for them told us about their experiences of living with poor health due to heart disease and about how well they thought health and social care services responded to their needs. We spoke to them in a series of interviews spread out over a year. We also interviewed the professionals nominated by the patients as most involved in their care at the same times to gain their views and suggestions about improving care. For my second study, we again interviewed patients with heart failure, their carers and key professionals up to three times over 12 months. This study focused more on whether health and social care services were organised and provided in ways that help people with advanced heart failure and their families the most. Advance care planning (planning ahead with patients and their families to try to make sure that when someone is dying treatment and care is given which is in line with that person's goals and preferences) has been recommended as part of palliative care developments in the UK. My third paper looked at advance care planning being offered by general practitioners to their patients with cancer and some other advanced conditions to try and understand more about whether it was helpful.

We need to identify people with deteriorating health who are at risk of dying so they can receive good palliative care. When people have advanced illnesses these are more unpredictable than cancer. I developed a guide called the 'Supportive and Palliative Care Indicators Tool' (SPICT) to help professionals to identify people with unmet needs who could be helped by a palliative care approach. I. My fourth research paper, reported a study testing the SPICT in a large teaching hospital. The SPICT was then used to identify people with multiple advanced illnesses for my fifth study. People who took part were interviewed to find out about their experiences of an emergency hospital admission and their care once they were back at home again. In my final paper, I described how we designed a pilot, randomised trial of future care planning with patients who had advanced heart disease and their informal carers.

This thesis presents a critical review of these six linked research studies. I have explained their background and importance in helping to make sure that research about patient and family experiences is used to improve their care.

## Acknowledgements

For the past 15 years, I have had the great pleasure and privilege of being a member of the Primary Palliative Care Research Group at the University of Edinburgh. It is as a member of this wonderful team of colleagues that I have gained the best possible training in palliative care research as we have worked on these studies and many other interesting and valuable projects. By sharing our experiences and learning with and from each other, we have achieved far more than would otherwise have been possible.

My mentor and friend throughout this time has been Scott Murray who has led our group with wisdom, integrity and enthusiasm combined with endless patience and persistence. He made it possible for a busy palliative care specialist to become a successful clinical researcher.

Thank you, Scott.

Marilyn Kendall and Allison Worth have taught me so much about qualitative research and the importance of listening to the narratives told by our patients and their families in order to understand their perspectives in new and critical ways. Bruce Mason has been a creative and lateral thinking colleague and Martin Denvir has shown us how to turn a supportive and palliative care intervention into a robust clinical trial. Other members of our research group have helped me along the way and each of them has made their own unique contribution to our combined efforts. Morag Edwards our superb administrator, keeps us all organised and like everyone else I could not manage without her.

Our group has benefited greatly from being within the wider umbrella of the Centre for Population Health Sciences, and I am grateful for the support, help and advice I have received over many years from Professor David Weller and Professor Aziz Sheikh.

Research and writing for publication is very rewarding but also time consuming and demanding work that has taken up many of our evenings and weekends. I could not have done it without the never-ending support and encouragement of Craig, Moira and Calum.

## Publications submitted as part of this thesis

1. **Boyd KJ**, Murray SA, Kendall M, Worth A, Benton TF, Clausen H. Living with advanced heart failure: a prospective, community based study of patients and their carers. *Eur J Heart Fail*. 2004; 6(5):585-591. (Thesis p71)  
<http://www.ncbi.nlm.nih.gov/pubmed/15302006>
2. **Boyd KJ**, Worth A, Kendall M, Pratt R, Hockley J, Denvir M, Murray SA. Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals. *Palliat Med*. 2009; 23(8):767-776. (Thesis p78)  
<http://pmj.sagepub.com/content/23/8/767>
3. **Boyd K**, Mason B, Kendall M, Barclay S, Chinn D, Thomas K, Sheikh A, Murray SA. Advance care planning for cancer patients in primary care: a feasibility study. *Br J Gen Pract*. 2010; 60(581):e449-458. (Thesis p88)  
<http://www.ncbi.nlm.nih.gov/pubmed/21144189>
4. Highet G, Crawford D, Murray SA, **Boyd K**. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care*. 2014; 4(3):285-290. (Thesis p98)  
<http://spcare.bmj.com/content/4/3/285.full.pdf+html>
5. Mason B, Nanton V, Epiphaniou E, Murray SA, Donaldson A, Shipman C, Daveson B, Harding R, Higginson I, Munday D, Barclay S, Dale J, Kendall M, Worth A, **Boyd K**. "My body's falling apart". Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Support Palliat Care*. 2013; 0:1–6.doi:10.1136/bmjspcare-2013-000639. (Thesis p104 )  
<http://spcare.bmj.com/content/early/2014/05/28/bmjspcare-2013-000639.full.pdf+html>
6. Denvir MA, Highet G, Robertson S, Cudmore S, Reid J, Ness A, Hogg K, Weir C, Murray S, **Boyd K**. Future care planning for patients approaching end-of-life with advanced heart disease: an interview study with patients, carers and healthcare professionals exploring the content, rationale and design of a randomised clinical trial. *BMJ Open*. 2014;4:e005021.doi:10.1136/bmjopen-2014-005021. (Thesis p110.)  
<http://www.ncbi.nlm.nih.gov/pubmed/25023130>

## Critical review

### 1. Introduction: palliative care for people with any advanced illness

*'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification, assessment and treatment of physical, psychosocial and spiritual problems'*

WHO 2002

It is now widely accepted that identifying people with advanced illnesses whose health is deteriorating in systematic and timely ways, assessing their unmet needs, and planning care with them are priorities given the demographic trend of ageing populations in the UK and internationally. This was not the case fifteen years ago when I embarked on the research presented in this thesis. Hospice based, specialist palliative care services were increasingly available in countries like the UK, USA and Canada, but most still focused on caring for people dying of cancer and a small number of neurological conditions. Hospice services were predominantly community orientated and aimed to support people dying at home or, if that proved to be too difficult, in a hospice inpatient unit. (1) The landmark American 'Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments' (SUPPORT), published in 1995, focused attention on the pressing need to improve care of seriously ill people dying with a much wider range of conditions and in acute hospitals. (2) The SUPPORT trial failed to show any impact from promoting advance directives and eliciting patient preferences on professional decision-making. (3) However, wider healthcare policy, research and education were starting to pay attention to patient perspectives in shaping and improving services instead of relying on proxy information from surveys of bereaved relatives. (4) A programme of research involving people living with common, advanced non-malignant conditions whose prognosis was just as poor as that of people with many common cancers was needed. (5) People with advanced long term conditions such as heart failure or end-stage chronic obstructive pulmonary disease were rarely in receipt of any form of palliative care. (6) Most of them were dying in acute hospitals during an acute

exacerbation of their condition despite spending most of the last year of life at home being looked after by general practitioners and other community based services. (7)

In 1998, a study of patient, carer and professional perspectives of palliative care for people with cancer in Scotland was being mooted by clinical academics, senior clinicians and policy makers in NHS Lothian. Inoperable lung cancer was selected as it was the commonest and most lethal malignancy in Scotland. Many people with lung cancer were diagnosed late and their illness followed the archetypical, rapidly declining cancer trajectory. (8) (9) I proposed including a comparison group of people with advanced heart failure recruited from the acute hospital where I was working as a palliative medicine specialist. Our in-depth study of the experiences of people with advanced lung cancer or advanced heart failure used a novel, longitudinal, qualitative approach to data generation and analysis. This consisted of serial interviews with patients, carers and their nominated key professionals at three monthly intervals for up to a year. We later published a description of this methodological approach. (10) We also integrated multiple narratives from different patient and professional perspectives to gain a broader understanding of people's evolving experiences and concerns over time. (11) A strength of working as a research team with complementary professional backgrounds (a primary care academic, a palliative medicine specialist, a nurse academic and a social scientist) was our ability to bring diverse perspectives to data interpretation and synthesis. (12) My clinical work seeing people with many advanced, progressive illnesses including heart failure, enabled me to bring valuable insights to the research process as our multidisciplinary research team read and re-read the interview transcripts, discussed emerging themes and reached consensus about the final data interpretation. This iterative process was a key part of the ongoing analysis that accompanied and informed data generation throughout the study. We published the findings of this study in the British Medical Journal and highlighted the different needs and experiences of people with heart failure and the lack of well developed models of care in comparison with cancer. (13)

## **2. Living and dying with advanced heart failure: experiences of patients, families and professionals. (Paper 1)**

*'I'm alive but it's no life...'*

(Patient with advanced heart failure)

In the late 1990's, nurse-led interventions to reduce hospitalisation and implementation of evidence-based, drug treatments for left ventricular failure dominated research efforts into the care of people with advanced heart disease. (14) (15) (16) A few smaller qualitative studies had explored people's information needs, their coping strategies and some of the challenges of communication and decision-making for people living with heart failure but only at single time points in the illness trajectory. (17) (18) However, it soon became evident in our comparative study of people with lung cancer and people with heart failure that my clinical impression of considerable unmet need among people living with advanced heart failure was present in our study group. I therefore decided to lead a secondary analysis of the data generated from the 20 patients who had heart failure to explore this further. The data, including the fully transcribed interviews, had already been entered into the qualitative data analysis package, NVivo, so could be accessed for this work. Reservations about subsequent analysis of qualitative data often centre on concerns that secondary analysts will lack the detailed, contextual knowledge about the circumstances of the original data collection held by the primary researcher who generated the data. Classically, secondary analysis involves analysis of data deposited in a research archive by a different research team. However, it is common practice for qualitative as well as quantitative data collected by one member of a research team to be analysed subsequently by others who were active participants in the research project. (19) An iterative process of data generation, interpretation, analysis and further data generation is central to the methodology of an in-depth qualitative interview study like this one. When I returned to the data, it was to look in more detail at the themes that had already emerged and to describe those themes relating to the experiences of people with heart failure in more depth. Being fully involved in the study from the beginning meant that I had already been contributing to data analysis and interpretation and fully understood the context of the study.



Patients and carers often recount their experiences in narrative form. Illness stories, such as those we heard, tend to have a beginning, middle and end with various specific events forming the plots and subplots in a temporal, causal sequence. Professionals are expected to describe patients they have cared for in terms of histories and formal case reports, but they also make frequent use of anecdotes and personal stories. (20) Use of a narrative analysis framework with our data was helpful in retaining the cohesion of individual stories about people's experiences while also looking for common and contrasting themes across the evolving accounts of patients, carers and professionals. In addition, the analysis of narratives provided a critical way of examining not just the accounts of individuals or groups (patients, carers, or professionals), but also norms and conventions such as concerns about openly discussing death and dying or the meanings attached to 'palliative care'. (21) (22)

A total of 112 interviews were available and comprised; patients (50), informal carers (27), professionals (30), bereavement interviews (5). A diverse group of 16 key professionals had discussed the interview findings as part of the original study and that transcript was also reviewed for data about care of people with heart failure. Many of the people that we interviewed were elderly, with multiple co-morbidities in addition to heart failure so they had much in common with the participants in my later studies (Papers 2, 4 and 5). (23) People often struggled with many dimensions of poor physical and psychosocial health, and they lacked information or any meaningful opportunities for care planning.

*'I slipped down the bed and I could not get my breath. I felt, oh I cannot really, you cannot tell people what it's like.'* (Patient 1)

*'The sickness makes me feel lousy. I am taking that many tablets now, you sort one thing out and it starts another.'* (Patient 3)

*'He is fading away before my eyes but it could be another year or two or it could be another week or two, or it could be tomorrow. I don't know.'* (Carer 6)

The care provided was often poorly coordinated and unresponsive to their needs with no evidence of proactive care planning or sensitive discussions about end-of-life care:

*'I suppose I am expecting it to be something catastrophic, so planning and discussing it is not really an issue.'* (General practitioner 14)

*'They told us they had a plan. They said, we have a plan that if she arrests we will not be resuscitating her. Just as if it was nothing. It was terrible.'* (Daughter of patient 7)

The focus group participants agreed that much needed to be done to improve care for people with advanced heart failure and highlighted several key factors to be addressed. Better information and a shared language for discussing the condition of heart failure would provide a good foundation for talking about the illness, its treatment and what might happen. Flexible models of holistic care that can adapt to different personal, family and illness circumstances were also deemed important as well as collaborative working between hospital specialists, primary care teams and specialist palliative care services. I concluded the discussion in my paper by proposing a holistic approach to patient and family care, integrated across primary and secondary care and delivered in parallel with active treatment of reversible underlying conditions. These recommendations have remained unchanged in the intervening ten years, albeit underpinned by a much larger evidence base to which my research has contributed. (24)

The accompanying editorial in the European Journal of Heart Failure highlighted the importance of recognising that conventional treatment does not prevent people with heart failure from having intrusive symptoms and a poor quality of life as they live with what is ultimately a progressive, terminal illness. Ward, a cardiologist himself, acknowledged that many heart specialists were treating patients in order to relieve symptoms or to prolong life and they assumed that this would improve its quality. The absence of a holistic view of patient and family concerns and experiences exacerbated this problem. While commending our research, he called for action to move forward from a better understanding of the problems and challenges needing to be addressed, into making concrete proposals for changing treatment and care. (25) I tried to respond to this challenge in the next study.

### **3. Developing services for people with heart failure and their families: a new framework. (Paper 2)**

*'I'm not frightened of dying, but I want to live...'*

(Patient with advanced heart failure)

In the first few years of the new millennium, advanced heart disease was more clearly identified as a major public health problem. (26) Substantial numbers of mainly older people were now living in the community with advanced heart failure and the additional burden of multiple co-morbidities. (27) Repeated hospitalisations and hospital deaths were common, and care was expensive but poorly coordinated. (28) At the same time, new policy documents and guidance were being developed to address the unmet needs of this patient group. Initially, these targeted delivery of evidence-based approaches to the medical management of people with left ventricular failure in an attempt to reduce morbidity and hospital admissions. However, acceptance that heart failure is a life-limiting condition with a poorer outcome than many cancers meant attention was finally directed towards supportive and palliative care. (29) (30)

It was therefore timely to extend the scope of our earlier work, take account of the new policy recommendations and explore the potential challenges of applying them in clinical practice. I led a grant application by our research group to the British Heart Foundation/ Department of Health programme and we started a two year study in 2002. Our goal was to integrate and explore the perspectives of a diverse sample of patients recruited in primary care and secondary care (cardiology and medicine of the elderly services), their informal carers, and the professionals caring for them. In addition, we sought to move from understanding people's experiences of health and social care service delivery to making concrete and practical recommendations that would inform future service developments. A combination of approaches to data generation and analysis best suited this aim. We again used a longitudinal, narrative analysis of case-linked interview triads and two qualitative researchers conducted 162 multi-perspective interviews with 30 patients, 21 family carers and 41 key professionals. (11) In addition, we convened three multi-professional focus groups to

gain a broad perspective of clinical and service management perspectives. A group of patients and carers from our local heart failure service users' forum also met to discuss the findings of the study and contributed to the final report. An experienced facilitator moderated the discussions and encouraged group interaction and problem solving. The interviews and focus group discussions were digitally recorded and transcribed for analysis with the aid of the computer package NVivo. Some focus group participants did provide further narratives that complemented those we had already generated from the interviews. However, we were particularly interested in hearing about suggest approaches to service redesign and improvement so we adopted a more ethnographic approach to analysis of the focus group data. This made it possible to retain a sense of the group discussion as a whole and the health and social care context within which the participants worked or lived. (31)

As in my earlier study, difficulty accepting the inherent uncertainties found in the illness trajectory of advance heart failure was widespread among patients, carers and professionals. (9) (32) (33) This delayed the identification of patients and hindered more open discussions about what might happen as their health deteriorated and how care could be planned and coordinated:

*'I think it takes a while for that penny to drop. We don't switch very well into palliative mode. We like to make them feel better.'* (Cardiologist 1)

*'If you'd asked me two and a half years ago if I thought she was going to be here this summer, I'd have said no. That's why I'd be more reticent about talking about dying with somebody with heart failure than somebody with cancer.'* (General practitioner, Patient 25)

As I will show later in this review, the problems associated with 'prognostic paralysis' remain one of the greatest barriers to integrated, early palliative care. Inequalities between people with left ventricular failure who received structured support from a key professional (usually a heart failure nurse specialist) and those who had other forms of heart disease or complex multi-morbidity were evident, as were the challenges of delivering effective shared care for people in the community. I will discuss participatory research and education in the next section, but this study was also based on an explicit commitment to engaging with our participants in ways

that would enable us all to work together to generate realistic solutions that might have a positive impact on the way care could be delivered and accessed in the future. Patients and carers we interviewed were sent a lay summary of the key findings with an invitation to add their thoughts and comments. The focus group participants were asked specifically to help me to develop and refine 'A service framework for coordinated care of people with heart failure' and it was published as an Appendix to the paper. (34) The Appendix was subsequently reproduced with permission in a position statement published after the 2009 palliative care workshop of the Heart Failure Association of the European Society of Cardiology. (35)

#### **4. Advance care planning in primary care is ‘easier said than done’. (Paper 3)**

*‘You can lead a horse to water, but you cannot make it drink.’*

English Proverb

By 2008, when I conducted my next study, advance care planning was being strongly advocated by NHS health policy makers despite limited research in the UK. The rise to prominence of advance care planning in end of life care can be traced back to the SUPPORT study I mentioned previously. This landmark study in American hospitals suggested that specialists and teams were not taking account of previously expressed wishes and preferences about treatment limitations when caring for people who were dying. (3) Advance care planning was seen as a structured process enabling people to make and document an advance refusal of life-prolonging interventions well ahead of the actual situation where those decisions would apply. This type of advance care planning gained support because it resonated with societal and cultural values of personal autonomy (enshrined in Patient Self-Determination Act of 1990). There was a consensus that people should have greater choice and control over their care at the end of life. In addition, patients, families, health professionals and policy makers were becoming increasingly concerned about the burdens and escalating costs of intensive hospital treatments in the last weeks of life and the ‘medicalisation’ of death and dying. Fried has traced the historical evolution of advance care planning in the USA. She highlighted the tensions between the two major factors underlying its endorsement as a key health policy. On the one hand, the drive to reduce the spiralling costs of care in the last months of life could mean that too much attention was being paid to deciding what treatments people would not get at the end of life. On the other, encouraging open dialogue about decision-making when people are deteriorating and dying has many benefits. (36)

Advance care planning internationally did evolve into a broader process of discussing and recording a person’s preferences concerning goals of care and it was widely promoted for people who may lose capacity or communication ability in the future. (37) In the USA, Australia and parts of the UK, advance care planning came to be seen as a central element of good palliative and end-of-life care. (38) (39) (40)

In an American multi-centre, cohort study of people with cancer and their carers, 37% reported having end-of-life discussions and this was associated with a lower rate of medical interventions and earlier hospice referral. (41) A small, randomised trial with elderly people in Australia showed an increase in patient's wishes being known and followed if they were admitted to hospital. (42) In the UK, the view that dying at home was the best and preferred option for many more people, led to place of care and place of death becoming the 'choice' most often discussed and documented as part of advance care planning. The intended outcomes were avoiding unplanned hospital admissions, reducing hospital deaths and facilitating a timely transition to holistic palliative care focused on quality of life. (43) People spend 90% of their last year of life living in the community and advance care planning discussions should ideally be offered when people are more stable and at home. Consequently, in 2009, UK national policy makers and the Royal College of General Practitioners proposed that all general practitioners should be required to identify the patients they considered likely to die in the next 12 months using the Gold Standards Framework and offer to discuss end-of-life care and advance care planning with those patients and their families. (44)

For my third study, we obtained a grant from Cancer Research UK to pilot a mixed-methods educational intervention on advance care planning for general practitioners. Mixed-methods approaches in palliative care research offer a valuable way to generate data from different and complementary sources that can be synthesised to build a better understanding of the complex and multifaceted experiences and situations found in real life clinical settings and are recommended in the initial phases of trial design. (45) The study focused on patients with cancer as they are more likely to be identified for palliative care than people with other advanced, progressive conditions and we recruited a diverse sample of practices. We appointed an experienced, social science researcher who was independent of the intervention to conduct the evaluation and attend the workshops as an observer to record field notes. I worked closely with the researcher throughout the study sharing the data analysis and interpretation with him. The researcher visited each practice before and three months after the intervention to explore barriers and facilitators to advance care

planning in primary care and elicit perceptions about the impact and effectiveness of the educational intervention. He asked the practice staff how they thought advance care planning could be integrated into their working practices and conducted semi-structured interviews with 20 general practitioners and eight community nurses. I have extensive experience of facilitating clinical communication educational sessions for health professionals so I led the workshop at each of the practices. We used a well established, evidence-based interactive communication teaching method in which participants generate scenarios from their own clinical practice and these form the basis of the simulated patient interviews used in the workshop. (46) (47) Each practice also received a resource pack consisting of consensus-based guidance on how to approach conversations about deteriorating health and planning for end-of-life care, information about advance care planning, copies of local palliative care guidelines, and a draft future care plan for use with patients and families identified by their general practitioners during the study. (48) One of the most striking features of the scenarios brought to the workshops was that the patients being identified by the participating clinicians for advance care planning seemed to be unaware of how ill they were. This left the primary care professionals facing the difficult initial task of breaking bad news about a poor prognosis before being able to move on to talking about end-of-life care planning. With a small study of this kind, it is important to look for generalisability beyond the study setting so the researcher discussed the study findings and personal experiences of advance care planning with a purposive sample of UK general practitioners with a special interest in palliative care (Macmillan GP facilitators). (49)

Our study participants supported many of the core principles underpinning the concept of advance care planning, namely respect for autonomy, provision of individualised information about prognosis, being able to offer people opportunities to talk about future care, and the value of using appropriate planning processes to avoid crises when patients are dying. They were very concerned about balancing their responsibility to share information about deteriorating health with allowing people to maintain positive coping strategies centred on living well in the present. Being expected to discuss a preferred place of care at the end of life was particularly



problematic for these primary care clinicians and seemed to them to disregard the reality of limited care options and the changing circumstances and preferences of patients and families. In common with other studies of advance care planning with primary care teams, their accounts of attempting these conversations were dominated by concern that discussing place of death before the illness was very advanced conflicted directly with promoting hope, maintaining normality and letting people enjoy as much of their remaining lives as possible. (50) (51) Similarly, our participants valued clear and consistent prognostic information from hospital specialists, used clinical judgement based on observable signs of deteriorating health to prompt a care review and planning discussion and were more likely to identify people with advanced cancer. (52) (53) A national survey of physicians caring for cancer patients also found that most preferred not to discuss end-of-life options with terminally-ill patients who were feeling well but would wait for symptoms to appear or until there were no more treatments to offer. (54) The future care planning document I developed for the study was modified in response to feedback from our participants and published as an appendix to my paper. Four general practitioners used the plan as an aide memoire and a fifth found it to be a helpful tool to support conversations with four of her patients. (49)

A recent systematic review from the Netherlands of the effects of advance care planning interventions on end-of-life care mainly identified studies that came from the USA and from institutional settings. The authors noted that many of the studies evaluated advance directives which were used less frequently in the UK and Europe. In the American healthcare context where the costs and burdens of ‘medicalisation of care’ at the end of life are a major factor for patients and families as well as service providers, having an advance directive did have a positive impact on the intended outcomes of reducing cardiopulmonary resuscitation, hospitalisation and intensive interventions. However, the evidence base for advance care planning per se remained poor. (55) Others have argued for a broader view that encompasses not just documentation of people’s anticipated wishes but a care planning process that shifts the focus from expecting people make premature decisions based on incomplete information to preparing patients and their surrogates for the types of decisions and conflicts they may encounter when they do have to engage the realities of end-of-life

decision-making. (56) (57) (58) It is interesting to see that our findings from six years ago resonated with the conclusions of another systematic review from Australia published in 2014. This review concluded that factors influencing the uptake of advance care planning in palliative care remain complex and multifaceted, with facilitators and barriers spanning the social and cultural beliefs of patients, families and health professionals, as well as the structural constraints of health and legal systems. (59) Patients and their families generally saw advance care planning differently from professionals and policy makers. For many people, advance care planning meant not only preparing for incapacity, but also preparing for death. Engagement with planning was not based solely on a desire for autonomy and the exercise of control. People were also concerned with relieving burdens that could be placed on others and planning ahead was seen as a social process that occurred within relationships with close loved ones. (60) To improve end-of-life care for an increasingly multicultural and aging population, we need to increase the flexibility of advance care planning and shared decision-making to encompass diverse perceptions of autonomy and improve communication and address emotional burdens for families when patients lack decision-making capacity. (61) Health professionals are called upon to find courage and competence in discussing, delivering and evaluating accessible and flexible systems of care that support what matters most to individuals rather than fitting people into reductionist, pre-conceived notions about what constitutes a 'good death'. (62) Pollock too has argued cogently that we need to move away from the widely promoted view that advance care planning should give priority to well-planned dying at home and replace this with anticipatory care planning that aims to enhance the quality of care offered to people who die in any care setting. (63)

Difficulty in identifying people whose health is deteriorating has remained one of the greatest problems restricting access to a palliative care approach and effective care planning for people with advanced conditions. This was the subject of the main study presented in this critical review and is discussed in the next section. In my final two papers, I will return to the subject of future care planning and differentiate between advance care planning and anticipatory care planning.

## **5. Identifying people with deteriorating health for supportive and palliative care assessment: development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT). (Paper 4)**

*‘Medicine is a science of uncertainty and an art of probability.’*

Sir William Osler

*“Prediction is very difficult, especially about the future”*

Niels Bohr, Physicist

Timely identification of people who are deteriorating and may die in the foreseeable future, assessment of any supportive and palliative care needs, and well-coordinated, future care planning in line with their goals and preferences are regarded widely as prerequisites for effective care and are key elements of health care policies in the UK and internationally. (64) (65) (66) (67) This is all the more pressing given the numbers of people dying each year who could potentially benefit from some form of palliative care. A population study estimating palliative care needs in England used linked mortality and hospital episode data to show that in high-income countries like the UK, 69%–82% of those who die could benefit from palliative care. Murtagh, Bausewein (68) Clark et al. conducted a detailed prevalent cohort study of just over 10,000 Scottish, acute hospital inpatients on a single day in 2010. (69) After 12 months, 28.8% of the patients had died: 3% by 7 days, 9% by 30 days, 21% by 6 months, and 26% by 9 months. The timing of those deaths followed a non-linear trajectory with 32% of all the deaths occurring during the index hospital admission and two-thirds happening within the initial 6 month period. Mortality rose steeply with age and was associated with social deprivation and multimorbidity. In frail older people, the risk of dying remained elevated during the 30 days after discharge from an unplanned hospital admission before returning to the population norm. (70) (71) Unplanned hospital admissions are an important indicator of deteriorating health, with a marked rise in admissions occurring in the final months of life. (72) It is equally important to offer better future care planning to people at risk of loss of capacity due to progressive illness. We also need to plan ahead with people who are very frail but apparently more stable, such as care home residents, because their final deterioration may be relatively sudden and “unexpected”. (73)

It is clear that uncertainty about the timing and outcome of acute episodes of deteriorating health in the final years and months of life characterises many illness trajectories including organ failure, frailty and multimorbidity. This unpredictable risk of dying commonly leads to delays in patient identification. (74) (75) (76) (77) (78) General practitioners and hospital doctors have reported difficulties in deciding when to introduce supportive and palliative care, particularly in patients with non-cancer illnesses. (52) (79) (80) In acute hospitals, frail older people were identified as likely to die within a year but this did not trigger the introduction of a palliative care approach to their care. (81) As I discussed in the previous section, advance care planning is seen as a key policy initiative in many countries and gives added impetus to the need for earlier identification. (59) Despite this, robust tools and triggers for patient identification are under-developed in contrast with other more established guidelines, processes of assessment and care management systems to support better palliative and end-of-life care in the UK and internationally. Failure of identification limits access to effective and appropriate holistic care for patients with unmet needs and hinders effective service improvements.

In 2010, I was invited to submit an article on recognising key transitions to palliative care for a peer reviewed supplement in the British Medical Journal. (82). The article included the first version of the Supportive and Palliative Care Indicators Tool (SPICT). (83) Working on this article started what to become a continuing interest in developing better approaches to patient identification. My fourth paper described the further development and evaluation of the SPICT. (84) To set this work in context, I will begin by discussing the evidence base for the five main approaches currently used to identify patients for palliative care and their underlying premises before going on to explain my rationale for developing a new tool (SPICT). This extends the literature review that I started for the 2010 paper and have continued as part of the wider SPICT programme. Systematic literature reviews of tools for patient identification are challenging because neither 'identify' nor 'identification' are MESH terms. (85) I used a combination of pragmatic, 'snowballing' approaches as I was primarily interested in tools for patient identification that were recommended for use in clinical practice. I sought expert opinion from UK hospital specialists and from palliative care specialists in the UK, Europe, Australia and North America

about the most commonly used tools in their field through personal contacts and professional networks. I also reviewed UK government policies and national guidelines including those from the National Institute for Clinical Excellence, the Scottish Intercollegiate Guidelines Network, the NHS Education Scotland Knowledge Network, and the Royal Colleges of Physicians, along with resources from the major UK palliative care organisations such as the Scottish Partnership for Palliative Care and The National Council for Palliative Care along with the European Association for Palliative care. Additional papers were identified through citation searching. Many tools and approaches were developed with the aim of improving prognostication based solely on clinician judgement which is known to have a relatively low correlation with actual patient outcomes. Some tools are also used to help plan or manage access to treatment and care. (86) (87) (88) Two systematic reviews on tools for patient identification for palliative care in primary care have been published, but none on tools for use in secondary care. (85) (89)

The five major approaches to prognostication and identification of patients for palliative care tend to be used in combination, and may be classified as follows:

1. Clinician judgements
2. Performance status based scores
3. Palliative care needs assessment tools
4. Disease specific mortality risk scores
5. Clinical indicators of advanced conditions

Most tools rely on application and interpretation by clinicians and some are used in combination. I will show how I drew on all five methods of identification in developing the SPICT. I also took account of the changing demography towards ageing populations with multimorbidity and tried to address the greatest barrier to patient identification of all, namely '*prognostic paralysis*'. This is the situation where clinicians delay identifying patients for palliative care assessment and care until death seems inevitable and there are no further treatments or interventions available to alter this. (54) (75) (90) (91) Finally, I will review the wider SPICT programme and its ongoing development and evaluation, not just in Scotland but internationally.

Before discussing the five approaches to prognostication and patient identification, I would like to refer to Glare's helpful definition. Glare rightly sets prognostication in a broad clinical context and draws on both the art and science of medicine. (87)

*'The physician's goal is to formulate an individualised prognosis for the patient starting with a generalised prognosis and modifying it using clinical observations, performance status, symptoms, co-morbidities, will-to-live and knowledge of illness trajectories.'*

#### 1. Clinician judgements

Clinician predictors of survival are inevitably subject to a degree of cognitive bias but remain a pragmatic and flexible approach to patient identification that is anchored in the realities of clinical practice. It is important to note that probabilistic predictions are less inaccurate than temporal ones. Clinical experience improves the accuracy of these judgements although a long period of involvement in the care of a patient can be a confounding factor. (92) In my own study of advance care planning in primary care (Paper 3) and in another study from the Netherlands, general practitioners used their experience to help them judge when it was time to introduce 'palliative care' but also relied on communication from hospital specialists about prognosis and treatment plans. (49) (53)

A tool that has been used widely in the UK and internationally for over 15 years when making clinical judgements about prognosis is the 'Surprise Question' (SQ). This was originally described by an American geriatrician, Joanne Lynn, as a way to identify people needing palliative care regardless of their illness trajectory. Interestingly, the early iterations of the SQ fully acknowledged the uncertainty of prognostication, particularly in relation to duration of survival. Lynn says:

'Instead of asking whether the person has a prognosis of some short limit (such as having a prognosis of six months, which Medicare regulations in the USA require if a patient is to qualify for reimbursement of hospice benefits), the clinical team asks, "*Is this person sick enough that it would be no surprise for the person to die within the next six months, or a year?*" Whether one looks a few months ahead or a year turns out not to matter much; at stake is whether the person is in a fragile enough condition that relatively minor

worsening or intercurrent illnesses could spell the end of life. Some of the patients identified by the “Surprise Question” will end up living for years in a fragile state, and some will die soon.’ (8)

The SQ has been used in many countries in primary and secondary care. Including the SQ as one of the core elements of the UK Gold Standards Framework (GSF) has contributed to its dissemination. (93) The wording of the SQ has been changed in the GSF to: *‘Would you be surprised if the patient were to die in the next months, weeks or days?’* The focus is therefore more on temporal prediction which, as Glare observed, is more inaccurate than probabilistic judgements. This has meant that the SQ is often interpreted as referring to a prognosis of less than a year. In their 2010 definition, the General Medical Council also directs clinicians to consider which patients might die within a specific time frame: *‘People are ‘approaching the end-of-life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days).’* (94) By making this shift in emphasis, these influential organisations have aligned the current SQ with other tools that focus on survival time. The original SQ concept of looking for people with a high ‘risk’ of deteriorating and dying has been lost. As a result, binary judgements tend to be made about whether a person should, or should not, be identified as requiring palliative care. Professionals and services may well be making decisions on the basis of prognostic judgements that turn out to be inaccurate and unhelpful.

Use of the SQ in patients with cancer and other advanced conditions in hospital and primary care settings has been evaluated in a number of countries but there is no published systematic review. In a 2010, outpatient clinic study, oncologists documented their response to the SQ in nearly 900 consecutive patients. At one year, 41% of the ‘No surprise’ group had died. The sensitivity of the SQ ‘no’ response was 75%, and its specificity was 90%. The positive predictive value (PPV) was 41% and negative predictive value (NPV) 97%. (95) In a similar study of community patients receiving peritoneal dialysis, 25% of identified patients died within a year; the PPV of the Surprise Question was 24.8% and its NPV was 93.4%. (96) In an Italian study, general practitioners used the SQ to screen their patients with advanced cancer and

reported one year survival. The study enrolled around 230 patients and the sensitivity of the SQ with sicker cancer patients was 69.3% with a specificity of 83.6%. Around 31% of SQ 'No surprise' patients survived beyond a year. (97) A recently published study from Japan screened over 2000 patients receiving palliative care in the community and hospitals for short term survival (7 or 30 days) using the SQ. They found that screening could identify many of the people who died within 7 or 30 days (around 90% sensitivity) but a high false positive rate meant that the SQ could not provide a definitive prognosis. (98)

One research group has raised concerns that the SQ may be particularly unsuitable as a tool to help general practitioners identify patients with COPD or heart failure for palliative care assessment and referral because of the uncertain nature of those illness trajectories and the difficulties primary care clinicians had in answering the question. They also commented that relying on temporal prognostication risks fostering a narrow view of palliative care as only being applicable at the very end of life. (99) In another qualitative study with general practitioners, participants were asked to identify two of their patients aged over 80 whom the GP thought were likely to die within a year for discussion. The GPs had difficulty making prognostic judgements unless the patient had a typical, rapidly declining cancer trajectory which was less common in their elderly patients. Most of them expressed concern that the Surprise Question was too subjective to be the basis for decisions about a poor prognosis. Pressure to use the SQ, meant that the general practitioners identified patients 'too soon' and before the time where they felt comfortable with considering advance care planning and terminal care. (100) The SQ may provide a means of articulating clinician judgements but its limitations in identifying people for a palliative care approach are evident.

## 2. Performance status based tools

Performance status or functional ability is long established in cancer care as a measure of disease status, a guide to treatment planning, and the most significant single factor in estimating survival time. (101) Combining a performance status score with the clinical features of a terminal cancer syndrome (anorexia, weight loss, dysphagia and cognitive failure) may improve the accuracy of prognostication,



particularly in the final couple of months of life. This is consistent with the archetypical cancer trajectory of rapid functional decline before death.(9) (102) Building on this, several statistical tools consisting of a Karnofsky performance status score combined with clinical and biochemical markers such as serum albumin and C-reactive protein have been developed and evaluated, largely in patients with cancer. (92) One of the most widely used tools of this type is the Palliative Performance Scale (PPS), developed by a Canadian hospice service in 1996 as a measure of changing functional status for use in palliative care services. (103) In a large, retrospective, cohort study of over 6000 patients referred to this specialist palliative care service, reasonable prognostic estimates could be generated for the majority of the patients via a nomogram that combined an admission PPS score with age, diagnosis, gender and place of care. However, the authors also acknowledged the limitations of a single measure of functional status in the context of evolving illness trajectories punctuated by ‘sentinel’ acute episodes of deterioration and noted that significant numbers of patients had a much shorter or longer than predicted survival times. (104)

More recently, a prospective, multi-centre study in 18 UK specialist services tried to develop and validate a new prognostic tool to improve or even replace clinician estimates of survival for patients receiving palliative care: the Prognosis in Palliative Care Study (PiPS). (105) Eleven core variables including performance status, clinical signs and blood tests predicted survival in terms of ‘days’, ‘weeks’ or ‘months’ in patients with advanced cancer more accurately than estimates by individual clinicians. However, the tool was not significantly more accurate than an assessment by the multi-disciplinary team. An expert consensus workshop concluded that a wide range of questions remain unanswered about the validity and clinical value of such prognostication tools. Stevinson, Preston (88) A recently published study has compared the Eastern Cooperative Oncology Group (ECOG) performance status scale with the Karnofsky performance scale, and the Palliative Performance Scale in a mixed primary cancer, outpatient cohort of people with advanced cancer and an estimated prognosis of under a year. All three measures of performance status predicted mortality risk effectively. Survival was approximately halved for each reduction in ECOG performance level. A simple performance status assessment is

practical in routine care and seemed to be as good as more complex measures requiring blood tests and calculations. (106)

### 3. Palliative care needs assessment tools

Holistic, needs-based methods of patient identification target people with poorly controlled, distressing symptoms despite maximal tolerated therapy and a range of other patient and family needs. The field of palliative care needs assessment has been dominated in recent years by the Palliative Care Outcome Score (POS). Like the shorter hospital Support Team Assessment Score (STAS), the POS was originally designed as a brief, practical tool to measure the outcomes of palliative care interventions from patient, family carer and professional perspectives. (107) The STAS measures symptom control, changes in the insight of patients and families and achievement of place of care preferences. The POS was developed from the STAS in 1999 and has been validated for measuring outcomes with patients who have a wide range of advanced illnesses and in many countries. POS can be used as a screening tool for unmet supportive and palliative care needs in patients already identified as having advanced illnesses and potentially needing palliative care or to complement other methods of data collection in studies of patient experiences of care. The assessment consists of 10 physical, psychological, information and care domains which are scored from 0 (best) to 4 (worst) for a recent period of time, the past 3 days. There is the option to add a patient's perceptions of what constitutes their main problems or needs. However, some patients, such as those with advanced COPD, tended to adapt to a high burden of symptoms and may not benefit fully from interventions utilising case finding based on a 'needs assessment'. (108) A group of patients attending a conservative renal management clinic reported a high burden of symptoms using the renal version of POS, but there was no relationship between the level of renal impairment and symptom prevalence, severity or quality of life. (109)

In Australia, needs-based assessment has been developed with the aims of promoting earlier identification of patients for specialist assessment and ensuring there is a robust approach equitable decision-making about ongoing access to specialist palliative care services. (110) Like the POS, the Australian NAT-PC tool assesses unmet needs across a range of physical, psychological, family/social and existential domains but does not attempt to identify those at risk of deteriorating and dying.

Needs assessment tools can be helpful in assessing the holistic care needs of individual patients as part of managing their care and in evaluating care or services. Theoretically, they should enable scarce specialist resources to be targeted towards those with severe and complex needs. At present, there is no standardised systematic, evidence-based and holistic approach to screening patients for supportive and palliative care needs. (111) Such tools are of less value in identifying people whose health is deteriorating generally or for prompting conversations about future care planning based on a change in the person's health or circumstances.

#### 1. Disease specific mortality risk scores

Disease mortality risk scores are used extensively by hospital-based specialists in their clinical practice and in health services research. These tools are often seen as the 'gold standard' for judging prognosis in patients dying with organ failure. Large population studies and refinement of the component measures have aimed to improve their predictive value but these tools vary in accuracy and perform less well at the individual patient level, particularly now that multimorbidity is an increasingly common confounding factor. In ischaemic heart disease, the most widely used scoring system is the Global Registry of Acute Coronary Events (GRACE) score which estimates risk of death or further myocardial infarction within six months of an admission with acute coronary syndrome based on age, blood pressure, heart rate, renal function, the severity of any concomitant heart failure and the incident cardiac event. (112) In a recent cohort study from New Zealand, the GRACE admission-to-6-month total mortality and mortality/myocardial infarction scores both overestimated event rates by approximately twofold. (113) For populations with predominantly left ventricular heart failure, the Seattle heart failure model gives an estimate of one-year survival using clinical characteristics (age, gender, systolic blood pressure, weight, ejection fraction and heart failure class) laboratory tests (such as haemoglobin and sodium) and medications, particularly diuretic dose. It does not apply in the growing population of people with right-sided or global heart failure but does now incorporate medications and implantable devices that may affect outcomes. (114) Another tool from the Canadian Enhanced Feedback for Effective Cardiac Treatment (EFFECT) study can be used to predict 30-day and 12-month mortality in patients hospitalised with heart failure of any type. Multivariate predictors of

mortality at both time points included older age, lower systolic blood pressure, higher respiratory rate, raised urea and low serum sodium. Other co-morbid conditions associated with increased mortality included cerebrovascular disease, chronic obstructive pulmonary disease, hepatic cirrhosis, dementia and cancer. (115) All these mortality risk tools are available in the form of online calculators making them easier to use.

The Global Initiative for Obstructive Lung Disease (GOLD) is one of the most widely used international systems to guide diagnosis, classification of disease severity and treatment in people with advanced chronic obstructive pulmonary disease (COPD). It uses post-bronchodilator airflow measurement (FEV1) and clinical factors, particularly exacerbations. A recent large study concluded that although the GOLD classification may be useful in targeting treatments, it does not predict mortality with sufficient accuracy to be useful in clinical practice or research. (116) An alternative prognostic tool used to predict mortality risk in patients with COPD is the Body mass, airflow Obstruction, Dyspnoea and Exercise (BODE) index. The BODE index uses the same measure of airflow obstruction as GOLD (FEV1), breathlessness is assessed using the modified Medical Research Council dyspnoea scale, and exercise capacity is measured using a 6-minute walk test. It predicts mortality and hospitalisation with exacerbations more accurately than respiratory function alone. However, formal spirometry is difficult for frail people to manage as are structured walking tests, and neither test is readily available in all care settings. (117) (118)

The Model for End-stage Liver Disease (MELD) score combines renal function with two markers of poor hepatic synthetic function, bilirubin and the prothrombin time international ratio. MELD is widely used to assess mortality risk in end-stage cirrhosis and to guide the selection of patients for transplantation. It is simple to calculate but fails to predict survival accurately in about 25-30% of patients. (119) The United Kingdom End-stage Liver Disease (UKELD) score includes serum sodium in addition to the MELD criteria and is the main tool used by UK transplant services. (120) Low serum sodium is a poor prognostic indicator in advanced liver disease but has multiple aetiologies. Both tools identify very sick patients where the risk of dying equates to the risks of transplantation. Concurrent palliative care

support should be considered routinely as many patients, even if they are listed as eligible, will not be able to receive a transplant due to shortages of donor organs. However, these scores are of less value in screening for patients who can benefit from an earlier palliative care approach alongside optimal management of their liver disease. (121)

The incidence of chronic kidney disease is rising in an ageing population. Population cohort studies show that poor renal function carries a high, all-cause mortality and increases deaths from cardiovascular disease significantly. Patients with chronic kidney disease and co-morbidities such as diabetes and hypertension are at 1.3 to 3.6 times more at risk of dying than patients without chronic kidney disease. (122) (123) The Charlson Co-morbidity Index (CCI) has been used widely in renal medicine to evaluate the impact of co-morbidities on outcomes in people with chronic kidney disease. (124) Factors associated with increased mortality rates in patients on haemodialysis include; age, dementia, peripheral vascular disease, low albumin, low body mass index and diabetes. (125) A detailed modelling study in the USA designed to predict six-month mortality for patients receiving haemodialysis so that they could be considered for funded hospice care, considered a wide range of variables including the Surprise Question and the Charlson Co-morbidity Index. Five variables were independently associated with early mortality: older age, dementia, peripheral vascular disease, decreased albumin and the Surprise Question when combined with the other variables. The other components of the CCI did not add value to the model. (126)

#### 5a. Clinical Indicators - overview

There are no valid mortality risk assessment tools for many conditions with a chronic, progressive but unpredictable trajectory such as advanced multimorbidity, end-stage neurological conditions, frailty or dementia. Prognostic judgements are normally based on clusters of clinical indicators. I will look at these four groups of advanced conditions in turn and discuss the clinical indicator tools that have been developed for use in primary and secondary care over the past decade.

Multimorbidity is increasingly common and has an important impact on the population burden of long term poor health and the risk of premature death. (77)

(127) Quantifying this risk is difficult, but poor functional status seems to be a major risk factor. (128) Consideration of a person's total burden of advanced illness is important and multimorbidity dominates the health status of older people. Advanced multimorbidity, as I will discuss in relation to my next paper, is a clinical scenario where there is great potential for better coordination of care and introduction of supportive care alongside measures that enable people to live as well as possible with poor and deteriorating health. In some patients with cancer, co-morbidities are very common and have a significant impact on outcomes. For example, patients with lung cancer frequently have underlying chronic obstructive pulmonary disease and heart disease. These long term conditions worsen cancer survival and result in a higher death rate from non-cancer causes. (129) A systematic review of clinical indicators of six month mortality in people with non-cancer illnesses, published in 2011, looked at 74 relevant studies and concluded that even though the illnesses differed clinically, a universal set of poor prognosis factors was evident. These included: poor performance status, advanced age, malnutrition, co-morbid illness, organ dysfunction, and hospitalisation for acute decompensation. Patients with 2-4 indicators generally had a 6-month median survival and this was not altered by treatment. (130) An expert group from the Minnesota Evidence-based Practice Center undertook a systematic synthesis of published evidence about the prevalence of eight overlapping geriatric syndromes and their association with survival and institutionalisation, and reviewed models predicting survival in elderly populations. A higher burden of illness, perceived poor health, low body mass index, dementia, frailty, and disability with poor functional status resulting in marked dependency in activities of daily living were all associated with unplanned admissions and increased mortality risk. (131)

People with advanced neurological conditions often have unmet palliative care needs. In some conditions, such as motor neurone disease, introducing some aspects of palliative care at diagnosis has been recommended and these patients have traditionally accessed hospice care in the UK more than those with other long term neurological conditions. Challenges in other neurological conditions such as advanced multiple sclerosis and Parkinson's disease include the longer trajectory of the illness, difficulty judging prognosis, condition specific treatment and care needs,

and care delivery by multiple specialists, primary care teams and social care services. 'Red flags' such as frequent hospital admissions (with pneumonia, recurrent falls or urinary tract infections), weight loss, swallowing difficulties and very poor functional status may indicate that a patient with an advanced neurological condition is deteriorating and could benefit from palliative care for symptom control, family support and care planning. (132)

The syndrome of frailty has been defined as a condition of increased vulnerability to stressor events. Frailty is associated with reduced physical and psychological reserves that are identified on the basis of clinical signs such as weight loss, frequent falls, immobility, muscle weakness/ poor grip strength and slow gait. Patients often develop delirium and incontinence. (133) Falls associated with femoral fracture are a particularly poor prognostic sign. (134) Frailty occurs predominantly in older people and is gaining recognition as a common and important cause of morbidity, unplanned hospital admissions and mortality. (135)

Dementia affects a substantial and steadily growing population of people with great potential to benefit from a holistic, palliative care approach and this has been recognised by the European Association for Palliative Care in a recent position paper. (136) The expert group agreed that timely discussion of the terminal nature of dementia as a progressive condition may enhance families' and patients' feelings of preparedness for the future. Advance care planning, as discussed in section 4, is particularly important in an illness where people will lose capacity as they deteriorate. As the condition progresses, goals of care gradually shift from life prolonging treatments, to maintenance of function and then towards a focus on maximisation of comfort. The EAPC group also acknowledged that prognostication in dementia is very challenging and that mortality cannot be predicted accurately so clinical judgment based on indicators of advancing illness was recommended. A prospective cohort study of older people followed up for a year after an unplanned hospital admission found that those with moderate to severe dementia had twice the risk of dying within a year than other patients, except for those with a low Waterlow score. This is a risk assessment for pressure area care needs based on measures of appetite, skin condition and mobility, so it is a marker of nutritional status and function. (137) Dementia follows a "frailty" pattern of decline, with patients

suffering progressively severe disability with a substantial decline in function in the last months of life. A variety of scales have been developed and validated for use in assessment and care of people with dementia. As the patient deteriorates, functional scales for evaluation of performance status and corresponding care needs are mainly used. (138) The Functional Assessment Staging (FAST) tool for Alzheimer's disease is widely used to assess people for hospice eligibility in the USA. Stages of severity are described as the person gets more dependent on others for help with dressing, eating and toileting before developing incontinence, becoming bed bound and losing the ability to communicate. (139) However, a systematic review found that the FAST tool was not a reliable predictor of 6-month mortality. Other tools include the dementia specific, Bristol Activities of Daily Living Scale (BADLS) and the more generic Barthel Index, first published in 1965. (140) (141) Being dependent on others for help with all activities of daily living suggests the person will have a shorter life expectancy. However, there is considerable variation in survival in people with dementia and some patients have an unpredictable episodic deterioration with infections, fractures or other complications from co-morbidities. This pattern is similar to that found in people who have physical frailty. Patients develop swallowing difficulties, lose weight and have episodic aspiration pneumonia or other infections and are at high risk of pressure sores as they deteriorate. Cognitive impairment and communication difficulties make assessment of needs more challenging. These problems require good symptom control and careful decision-making as part of a holistic palliative care approach whatever the person's predicted survival. (142)

#### 5b. Clinical Indicators – tools

In 2001, Lynn published a discussion paper critiquing the 1996 USA National Hospice and Palliative Care Organisation eligibility guidelines in people with the variable illness trajectories associated with advanced non-cancer illnesses. These guidelines consisted of a series of clinical indicators of advanced illness in the four major types of organ failure (heart, kidney, lung and liver), dementia, and stroke disease. She highlighted the problems associated with seeking to identify people accurately as having a prognosis of less than six months. These people would be eligible for hospice services funded by Medicare if they were no longer receiving



disease modifying treatment. (143) However, these hospice referral guidelines have been used as the basis for other tools designed to help clinicians make decisions about when to refer patients for palliative care or introduce a generic palliative care approach. The most notable is the Gold Standards Framework (GSF) which I shall review in more detail because it is widely used in the UK and internationally. The GSF combined use of the Surprise Question with clinical indicators derived from the American Hospice criteria. This approach started in 1998 as a UK primary care initiative aimed at improving palliative care in the community through a structured process of patient identification, assessment and care planning. The GSF is now an independent organisation delivering a large, international programme of training, resources and accreditation from a designated GSF centre in England. There are specific versions of the GSF designed for use in different care settings, including hospitals and care homes, and to support care of people with dementia. (144) The GSF currently uses a 'Prognostic Indicator Guidance' (GSF-PIG) tool to help health care professionals identify patients for a palliative care approach. Clinicians are advised to decide on the urgency of assessment and care planning based on how close to dying they perceive the patient to be guided by a traffic light system of green, orange and red coding. This unfortunately highlights dying as the primary driver for urgent assessment and focuses users of the GSF-PIG on a need to make prognostic judgements before introducing palliative care. (93) The GSF-PIG consists of three elements: the version of the Surprise Question that looks for a prognosis of days, weeks or months; general indicators of decline and increasing care needs suggested by a list of 11 items including deteriorating functional status, increasing care needs, co-morbidities, symptoms, lack of treatment reversibility, weight loss, hospital admissions, acute events, low serum albumin and patient choice; and finally specific clinical indicators of advanced disease for cancer, three of the main types of organ failure, advanced neurological conditions which are classified under the 'erratic trajectory' of organ failure instead of being in the third 'gradual, prolonged decline' group of people with frailty and/or dementia or stroke disease. Evaluations of the GSF programme have been largely descriptive or cohort studies in primary and secondary care looking at its value in judging when to introduce palliative care. A review of the GSF programme (2001-2009) published by the National GSF team in

2010 described the seven core outcomes of the Gold Standards Framework and looked at evidence of its effectiveness. They found that the GSF improved care processes in primary care but the impact on patient outcomes was not clear so a new online 'After Death Analysis' audit tool was developed to address this. (145) The Gold Standards Framework Care Home programme evaluation used this post-death audit methodology and found that more patients died in their care home after introduction of the GSF programme. As a structured, palliative care intervention in a care setting like that with a large number of people in poor health at high risk of deteriorating the GSF approach appeared to be effective. (146)

Other services have also used the GSF-PIG to assess prognosis and identify patients for palliative care. A prospective cohort study of patients admitted with acute coronary syndrome compared the mortality rate over one year in patients identified with the Surprise Question, the GRACE score and one general plus two heart disease indicators from the GSF-PIG tool. (147) All three approaches had a negative predictive value of over (90%). Using a combination of the GRACE score and GSF-PIG gave a PPV of 44% and was much better than either tool alone or the SQ alone at only 16%. Another study of Scottish patients being managed by nurse specialists in the community compared the GSF-PIG with the Seattle Heart Failure model and found that neither tool accurately predicted which patients were in their last year of life although 86% of the patients did meet the GSF-PIG criteria for the last year of life. However, also having chronic kidney disease was a univariate predictor of 12 month mortality, with a sensitivity of 56% and specificity of 72%. (148) In survey of palliative care needs in two English acute hospitals, data were obtained for just over 500 patients well enough to consent or who had a proxy consenting, a 38% response rate. The case notes were reviewed using the GSF-PIG criteria, ward staff were asked to identify patients with palliative care needs and patients or a family member completed a needs assessment tool. The participants were predominantly older people with multimorbidity who had experienced multiple hospital admissions. 36% of these relatively 'well' patients had two or more general or condition specific GSF-PIG indicators and there was objective evidence of unmet palliative care needs in the patient questionnaires. Staff answering the Surprise Question judged that around 40% would die within a year. However, they thought that less than 20% had any

‘palliative care needs’ and few patients had evidence of a holistic palliative care approach to their care other than a DNA CPR form (29%). (81)

Two recent systematic reviews have identified three other clinical indicator tools in addition to the GSF and the SPICT for use in primary care and I will consider these next. (85), (89) Maas also surveyed members of the European Association for Palliative Care Primary Palliative Care Network. In the Netherlands, the RADboud indicators for Palliative Care (RADPAC) tool was developed via a three-step process; a literature search, focus group interviews and a modified Rand Delphi study. The purpose of this tool is to improve the care of people with advanced, progressive chronic illness in the community by enabling general practitioners to identify them and introduce more effective palliative care. Like other tools, it contains general and disease-specific assessment criteria, but only for cancer, COPD and heart failure. (149) The NECPAL-CCOMS-ICO tool was developed in Catalonia (Spain). Drawing on the SPICT and GSF-PIG it uses a public health, population screening paradigm for its design and evaluation. The NECPAL tool pays attention to psychosocial needs, geriatric syndromes particularly frailty and dementia, and signs of progressive functional and nutritional deterioration as well as indicators from all the major illness groups. Prevalence screening was carried out by the research team who interviewed clinicians in the community, care homes and acute hospitals. The clinicians were told to identify people with advanced, chronic conditions, choose those they judged to be at risk of dying within 12 months (SQ positive) and then look for one or more clinical indicators of palliative care need. By using the NECPAL in this way, the group identified 1.3% of the eligible population and 7% of those over 65 years. (150) A follow-up, cross-sectional study in the same region of Spain identified a prevalence of 1.5% of palliative care needs using NECPAL screening. Positive identification was mainly attributable to advanced frailty and general clinical indicators of deteriorating health irrespective of individual underlying conditions in those patients. The NECPAL tool contains detailed disease related indicators and scores taken from other prognostic tools including performance status scores. Some of the tests would require hospital-based, specialist assessment. The value of adequately mapping population needs for palliative care as the basis for improving care is emphasised in this model. However, the Surprise

Question is central to the tool and it was developed with the intention of improving temporal prognostication (death within a year). More recently the group has highlighted the difficulties of making accurate prognostic assessments for individuals as opposed to populations. (151)

In 2008, the American College of Physicians published evidence-based guidelines to improve palliative care after a detailed literature review spanning 1990-2005. They were unable to identify any evidence-based tools that have been validated and shown to predict the optimal timing to initiate palliative care services. (152) Indeed, I have only been able to identify one generic tool developed specifically for the acute hospital setting and designed to support patient identification for both general and specialist palliative care. (153) The Center to Advance Palliative Care in Wisconsin convened a consensus panel to select criteria by which patients at high risk for unmet palliative care needs can be identified in advance for a palliative care screening assessment. The consensus panel developed primary and secondary criteria for two checklists: one to use for screening patients at the time of admission and one for daily ward rounds. The admission indicators were those that are now widely accepted including multiple hospital admissions, refractory symptoms, complex care needs, deteriorating performance status, weight loss, and the Surprise Question. They chose a fairly simple list of illness rather than disease related secondary indicators including admission from a care home or hospice programme, long term oxygen use, advanced cancer and frailty associated with both cognitive impairment and hip fracture. The daily review list focused more on symptom control, complex care needs and challenges around goals of care and treatment decision-making. These align well with the role and expertise of a hospital specialist palliative care team and are effectively referral criteria. The report authors rightly recognise the need for a combination of general and specialist palliative care competencies, if the substantial proportions of hospital inpatients that need some form of palliative care are to receive it.

### **Developing the Supportive and Palliative Care Indicators Tool**

The challenge of finding suitable tools and approaches for use in routine, busy clinical practice in the community, care homes and hospitals with patients who

increasingly have not one but multiple advanced, progressive conditions is clear from this overview of the tools being used in the UK and internationally. But why develop another tool? My goal was to design a simple tool containing well-established, evidence-based clinical indicators that would be feasible, acceptable and applicable in all care settings. This tool would be able to prompt more effective, consistent and timely identification of all patients with deteriorating health due to advanced progressive illnesses such that they are at risk of dying. It would support but not replace clinical judgements made by health and social care professionals about their patients. A simple identification process is combined with suggested actions for professionals so that more people can benefit from integrated palliative care assessments and conversations about future care planning.

The six general indicators of declining health found in the SPICT were chosen on the basis of their inclusion in many of the tools in the five approaches to patient identification that I have reviewed above. These SPICT general indicators have remained largely unchanged since the original 2010 version of the SPICT. (154) We have only made some minor word amendments as a result of collaborative working with our SPICT partners across the UK, in Australia, Canada and some European countries. These ensured that the SPICT would be equally effective in other healthcare systems and when translated into other languages but did not alter the fundamental meaning of the indicators. Table 1 shows how the SPICT general indicators map to other published tools for individual conditions discussed above.

Table 1: Mapping the SPICT general indicators to ‘prognostic’ tools

<b>SPICT Indicators</b>	Cancer	Heart failure	Lung disease	Liver disease	Kidney disease	MM <sup>1</sup>	Frailty	Dementia	ND <sup>2</sup>
<b>Poor performance status</b>	X	X	X			X	X	X	X
<b>Dependency on others for most care needs</b>						X	X	X	X
<b>Weight loss</b>	X	X			X	X	X	X	
<b>Persistent symptoms despite optimal treatment</b>	X	X	X	X		X			
<b>Multiple unplanned hospital admissions</b>		X		X		X	X		X

MM<sup>1</sup> = multimorbidity

ND<sup>2</sup> = neurological disease

The six SPICT indicators are found in all four of the most widely used clinical indicators tools from primary and secondary care (GSF-PIG, NECPAL, RADPAC, and Wisconsin). Some professionals find that these 6 general indicators are sufficient to enable them to identify people for proactive assessment. Other professionals and specialist teams prefer to combine screening using the general indicators with looking for clinical evidence that the patient has one or more advanced, progressive illnesses. The advanced conditions section of the SPICT describes clinical indicators drawn from disease related mortality tools for organ failure (heart, lung, liver and kidney), advanced neurological conditions, dementia and frailty. Indicators found in these advanced conditions that are already covered by the generic indicators section are not repeated. An important aspect of the international SPICT project has been use of the website to build consensus across disciplines and countries about what wording should be used so that the indicators are described in ways that convey a consistent meaning. Six principles underpin the conceptual design of the SPICT.

**Designing a clinical tool for patient identification: SPICT**

1. Simple format and clinical indicators that are easily identified.
2. Contains evidence-based, general clinical indicators of deteriorating health and key indicators of advanced conditions (including multimorbidity).
3. Good face validity for health and social care professionals working in hospital, community, care home and hospice settings in the UK and internationally.
4. Prompts assessment of unmet supportive and palliative care needs as part of routine clinical practice.
5. Promotes early supportive and palliative care integrated with optimal management of any underlying conditions.
6. Contains accessible language and concepts that can be used to start conversations with patients and families about goals of care and future care planning.

The SPICT returns to the principles that were, in my opinion, articulated so well by Lynn and Glare when they explored the inevitable uncertainties of illness trajectories through the final years and months of life. (87) (143) Use of the SPICT addresses the requirement in all care settings for there to be much more systematic identification of

people with advanced conditions, deteriorating health and a risk of dying who often experience an illness trajectory that is neither linear nor predictable. SPICT-identified patients have an individual risk of dying which changes over time, and an individual set of care needs. For example, anyone with an advanced condition that leads to loss of capacity should be offered early discussions about future care planning regardless of temporal prognosis. Unlike the SQ, as it currently used, the SPICT is not intended to offer a binary yes/no answer to questions about whether a patient has a short enough prognosis to be identified for a palliative care approach. Using SPICT as a screening tool therefore differs from the rather linear ‘traffic lights’ approach of the Gold Standards Framework which links urgency of assessment to how close to the death the patient is judged to be. (93) The GSF guidance maps well to a more predictable, rapidly progressive, cancer illness trajectory but it is less helpful for screening the growing population of frail older people with multimorbidity.

The urgency of assessment depends on clinician judgement about the patient’s current needs and situation. A patient recently discharged from hospital with ongoing complex care needs due to rapidly deteriorating performance status or a patient with persistent, poorly controlled symptoms would merit more urgent assessment regardless of how close to death they may be. The SPICT indicators can therefore help to prioritise people with multiple, complex or more pressing problems for urgent needs assessment and care planning. Supporting and developing the effective general palliative care that is part of the role of most health and social care professionals working in the community and in care homes and of many hospital specialists is vital so the SPICT lists some of the most important aspects of assessment and care planning that they should consider for their patients. Identification with the SPICT is only intended to prompt specialist palliative care referral (or referral to other types of specialist service) if additional expertise is required. (155)

Having developed the SPICT based on published evidence and ongoing peer review, it was of course important for me to test its utility and validity in clinical practice and my fourth paper presents the findings of this research. Highet, Crawford (84) I chose

a mixed-methods participatory approach that drew on the principles of action research as the basis for this study. Action research focuses on generating solutions to practical problems. Participating clinicians become co-researchers working in partnership with the research team. Together they are actively involved in a cyclical process of data collection, analysis and interpretation. (156) (157) We ran the study in a large tertiary hospital and worked with the multidisciplinary team in four specialist units in turn. Each unit cared for people with one of the four major types of organ failure. Emerging findings were fed back to the clinical team for their comments after each of the eight week study periods and to all the units as they joined in the study. This provided us with an in-depth understanding of the way the SPICT indicators were being used and interpreted by hospital specialists who had expertise in using some of the other methods of identification reviewed above.

Table 2: Summary of SPICT evaluation study methodology

<b>Literature review</b>	<b>Peer review</b>	<b>Case study series</b>
Regular review of major UK and international palliative care policy websites.	Open access website with SPICT™ study information and the current version of the tool.	Screening all unplanned hospital admissions of patients with advanced conditions in four specialist units (renal, liver, cardiac, respiratory) using SPICT™ criteria; comparison with standard tools: SPARRA (Scottish readmission risk score), Charlson Index (renal), UKELD score (liver).
Ongoing targeted literature review of papers on patient identification for palliative care.	Open invitation to interested clinicians and policy makers in the UK and internationally to comment on SPICT™ content and join the project.	
	Promotion of the SPICT™ programme at UK and international conferences and through peer to peer contacts made by SPICT™ collaborators.	Six month follow-up of 130 identified patients from the four units for clinical and service use outcomes. Retrospective analysis of service use in last six months for 62 patients who died within 12 months.
	Mailing list of collaborators receiving regular updates about the SPICT™ who wished to use it in their own practice and contribute to ongoing development through multiple cycles of review and redesign.	An in-depth, qualitative study of the admission and discharge processes of SPICT™ identified patients in the four units including interviews with patients, carers and GPs, staff questionnaires and ward observations.



Using the SPICT enabled ward medical and nursing staff to identify patients. Non-medical members of the team felt more empowered to ask the medical staff questions about future care planning for the people they were identifying. Previously ignored inconsistencies in the approach to medical decisions about cardiopulmonary resuscitation were raised by nurses and led to more open discussions in the renal and liver teams about what constituted 'ward level' care. The 130 SPICT identified patients from the four units were followed up for 12 months. After 6 months 45/130 (35%) had died and by 12 months there were a further 17 deaths (62/130, 48%). We attempted to screen all unplanned admissions to each unit but this was only possible in the renal and liver units and we were unable to obtain data on all deaths for each unit at 12 months. Our primary objective at the outset was to test the utility and feasibility of the SPICT in clinical practice and not to evaluate its prognostic predictive value. This could be done in future studies, bearing in mind the limitations of this approach to patient identification that I have already discussed. Patients who died within the first six months had a higher number of clinical indicators overall but the pattern of these varied by illness group. Almost all the patients with advanced respiratory disease had a poor performance status (96%) and many also had poorly controlled symptoms (75%). Patients with liver disease were the most likely to have had two or more unplanned admissions in the previous six months (74% of that group). A third of the renal group had significant weight loss but this was uncommon in patients with cardiac or respiratory disease. These findings support clinician judgement, informed by a series of key indicators, as an effective approach to screening patients with long term conditions for deteriorating health and unmet holistic needs.

The SPICT is primarily a descriptive tool designed with, and for use by, practising clinicians to assist clinical judgements. Face and content validity are of primary importance. By building up a diverse, online peer review group, I was able to address validity further through drawing on expert opinion in the selection of indicators and the wording chosen to describe them. A Delphi survey uses a series of rounds of questions sent to a panel of experts to try to build consensus.(158) This approach has been used to derive a basic dataset for describing a palliative care cancer population.

In that study, a large panel of international experts took part in five structured rounds questionnaires to reach 70% consensus on a set of variables. (159) However, I decided that Delphi methodology would be too prescriptive and restrictive for a flexible, iterative process of dialogue and debate about clinical constructs and the language and meaning of the terminology used to describe them in the UK and internationally. The SPICT online group members numbered over 30 clinicians from different disciplines who were working in specialist palliative care, hospital specialties and in primary care. They provided ongoing peer review of each version of the SPICT that was developed during the evaluation study and their comments were integrated with those of the participating clinical teams. By the end of the project, no further changes were proposed to the indicators. Peer review and discussion about the SPICT indicators has continued via the website and is reflected in subsequent minor amendments to the ways in which the indicators are described. This was necessary because the SPICT is now being used widely outside the UK National Health Service. (Appendix C: SPICT 2015)

Criterion validity compares new tools with established measures. In my SPICT study group, I chose a key indicator of deteriorating health (unplanned hospital admissions) in the cohort of patients identified by the clinicians using the SPICT. In a comparison with the population based Scottish Patients at Risk of Readmission and Admission (SPARRA) score provided by Information Services Division (ISD) I found relatively high mean SPARRA scores of 65% in the SPICT identified group who died and 60% in those still alive at 12 months. (160) Comparisons with the Charlson renal co-morbidity index for patients with kidney disease and the UKELD score for the liver unit patients confirmed that SPICT identified patients had a high mortality risk as assessed with these tools. (120) (124) The Surprise Question is a widely used measure, so we asked participating clinicians to answer the SQ for each patient who had SPICT clinical indicators present. Use of the SQ identified 79% of the 62 SPICT identified patients who had died by 12 months but 71% of the SPICT identified group of 130 patients as a whole; a sensitivity of 79% but a low specificity of 29%, in keeping with the studies I have discussed earlier. Reliability (the degree to which an assessment tool produces stable and consistent results in multiple tests and by different users) is harder to evaluate in relation to tools such as the SPICT which are

based on qualitative descriptors combined with professional judgements. We asked our participating teams to use the SPICT indicators to help them make assessments as they would do in routine clinical practice to test the utility of the SPICT. Future studies could be designed to compare assessments made by multiple clinicians. The SPICT identified patient group demonstrated the same non-linear illness trajectory as that found in a large, Scottish inpatient cohort study. Clark, Armstrong (69) However, the SPICT identified patients had a higher risk of dying than the cross-sectional cohort of hospital inpatients evaluated retrospectively by Clark et al. (35% v 21% at 6 months and 48% v 29% by 12 months). As in the population survey, more of the patients we identified died within the first 6 months of follow-up than in the subsequent 6 months.

My own specialist palliative care team works in the participating units so I needed to be mindful of potential bias and conflicts of interest in data generation and interpretation. A social scientist was employed to undertake qualitative interviews and observations in each ward area. A purposive sample of 20 SPICT™ positive patients with diverse demography and clinical history was identified by ward staff and recruited for interview at home soon after discharge, four of whom died and two withdrew. Nine carers participated in a joint interview and ten of the patients' general practitioners were interviewed by telephone. The researcher attended daily and weekly meetings and ward rounds, supplemented by periods of direct observation in each unit using a modified version of The Workplace Culture Critical Analysis Tool (WCCAT). (161) The WCCAT observation approach in clinical settings is a form of ethnography: a research process where a trained observer enters an area and seeks to gain multiple perspectives of what is happening in that setting through detailed observations, and derive explanatory descriptions of the underlying culture. The WCCAT is used to enable staff to gain a greater understanding of workplace culture that can then inform practice development and a participatory change process. It was well suited to this project where we wanted to introduce a new tool for patient identification but also facilitate wider changes in attitudes and clinical practice among the staff. The patient/ carer and GP interviews were digitally recorded, transcribed and entered into the qualitative data analysis package NVivo

along with data from individual staff perspectives and ward/ team meeting observations. The researcher and I read the transcripts and we worked together to develop a thematic analysis framework identifying key issues relating to the patient journey through admission, inpatient care, discharge and follow-up in the community using a priori research questions derived from key palliative care policy documents as well as emergent issues raised by interviewees. Contrasting themes and issues were examined with a view to developing explanations of participants' experiences and understandings, initially from different perspectives and then synthesised across all participants. These data were not included in the paper that forms part of this thesis but provided valuable insights into the wider aspects of effective, early palliative care of which identification is only a part. As in my study of anticipatory care planning with general practitioners (Paper 3), and my next paper reporting the experiences of people with advanced multimorbidity following hospital discharge (Paper 5), attitudes to living with advanced illness and the negative connotations associated with 'palliative care' were of prime importance in influencing the behaviour of professionals, patients and family carers.

Before discharge, nursing staff prepared patients and families for the likelihood of further admissions and gave advice about warning signs of deterioration and strategies for dealing with these events. Care planning stopped short of a broader discussion about goals of care or proactive anticipatory care offering holistic support at an earlier stage alongside medical treatment and social support at home. Patients and carers varied in their coping strategies. Some minimised the symptoms associated with their condition and others tried to protect close family members:

*I wasn't even aware that I had it. I think they mentioned up in the (hospital) months and months ago, that there was a slight something. But they sorted it with medication.... I don't think there's anything up with my kidneys at the moment. Is there? (Renal: Patient 2)*

*I don't really talk to [husband] very much about it, because I don't want him to get any more worried, because he gets very depressed. So we don't talk about it all that much. But, I talk to my sister a lot. And my home help, she's a gem. (Renal: Patient 1)*

Many people seemed to cope with the emotional strain of living with a chronic life limiting condition through a process of 'positive denial'. People who adopt this

strategy have an accurate perception of their prognosis but dissociate that awareness from its personal impact, preferring instead to ‘hope for the best’ and ‘take each day as it comes’. Others would have liked more open conversations:

*‘I think in the long term my kidneys are not as good as they should be and they won’t improve. They’ll possibly deteriorate a bit. But I’m not worried about that, I’ll cross that bridge when we come to it. I think if I thought about it you would go round the bend.’* (Renal: Patient 5)

*‘I’m past thinking about it. Just got to get on with it, just, kind of a positive attitude...’* (Respiratory: Patient 1)

*‘At first it was very strange, very daunting. I was scared, like, to go out. Even if someone was just coming to talk your feelings through, you know, like, when I asked if I was going to die, no-one ever mentioned it again, it was, sort of, put to the side.’* (Liver: Patient 1)

Professionals described the difficulties of attempting to address future planning with patients whose coping mechanisms seemed to them to leave little room for open discussion. Senior nurses tried to use triggers such as an unplanned hospital admission to ‘plant a seed’. Other, less experienced staff said they lacked the necessary skills and confidence to initiate such discussions with patients and some felt that it was beyond their remit. Overall, there appeared to be a strong belief that few patients with these advanced, non-malignant conditions wanted to engage with a specific discussion about end of life issues in advance. Yet, some of clinicians clearly struggled with concerns about the burdensome nature of life-prolonging treatment in people who were clearly deteriorating.

*‘You wouldn’t do it to your dog’* (Renal: Consultant 1)

It seemed that little had changed since my earlier studies (Papers 1-3). Palliative care remained strongly associated with treatment withdrawal and dying amongst patients and professionals in primary and secondary care. Negative perceptions about openly discussing death and dying are a significant barrier to effective communication and care planning. (162) Few of the patients we interviewed were on a primary care palliative care register, although one general practitioner did highlight the importance of changing the focus of care, and another looked to hospital discharge information for guidance as in my third study:

*'I don't know. I think it's unlikely she'd be on the register because she doesn't have a diagnosis like cancer, and certainly not at this stage.'* (Liver: GP 2)

*'She wasn't in the terminal phases of dying. She is very much alive and has things to live for.'* (Respiratory: GP 2)

*'I think there's a lot more could be done for these patients with advanced non-malignant disease. With cancer patients it's a bit more of a well established pathway. You want to know if there's been any "major hiccups" during the admission, what the patient's been told, and if there's anything they expect us to do for follow-up.'* (Renal: GP 7)

This was a successful, mixed-methods study evaluating a simple, clinical tool (SPICT) based on readily identifiable indicators to support identification of patients with advanced conditions and unmet care needs who were at risk of deteriorating. Multi-professional teams were able to identify patients as part of their routine clinical practice and we found that those patients had multiple unmet supportive and palliative care needs and a high risk of both re-admission and dying. By the end of the study, we had modified the SPICT by improving the clarity of the language used for the descriptors. We decided not to include the Surprise Question because of its focus on temporal prognostication and its low specificity and we removed blood test results that were difficult to obtain and interpret in all care settings. The SPICT is available to download from a designated, open access website ([www.spict.org.uk](http://www.spict.org.uk)) and is grounded in the realities of clinical practice. This has led to the SPICT being adopted widely in the UK and internationally. It has been endorsed by many individual clinicians, professional organisations, health policy makers in Scotland, England, Ireland, several member states of the European Association for Palliative Care (facilitated by translations into French, German, Spanish and Dutch) and in Australasia. Future studies may include mapping SPICT indicators in prospective population studies of people from different care settings, inter-rater reliability testing, and use of SPICT in palliative care intervention trials.

## **6. Multimorbidity is now the norm, but ‘planning for dying’ is not. (Paper 5)**

*‘It is much more important to know what sort of patient has a disease than what sort of diseases a patient has.’*

Sir William Osler

After completing my evaluation of the SPICT in an acute hospital setting, we went on to conduct a multi-site, ethnographic and serial interview study of care coordination provided for people with advanced conditions recruited in an acute medical admissions unit in Scotland, a large primary care team in the north of England and a respiratory medicine team in London. The study was funded by the National Institute for Health Services Research (08/1813/258). Three social science researchers worked collaboratively and conducted ethnographic observations in the study sites, qualitative interviews with a purposive sample of patients, their carers and case linked professionals, and consultations with service providers. Patients were identified by the clinical staff using SPICT clinical indicators to guide an assessment of whether they thought the patient was deteriorating and at risk of dying within about a year. We found little evidence of any systematic approach to introducing supportive and palliative care except for the patients with lung cancer attending the respiratory medicine clinic. Fragmented care coordination due to poor identification of patients with multiple health problems and at risk of deteriorating and dying was the norm. The mean age of the 56 people recruited was 71 years (range 41-92) and by nine months 29% had died. (163) Many of those identified by the health professionals were frail, older people with multimorbidity. Working with the study lead researcher, I therefore undertook a secondary analysis of the data generated from 87 serial interviews with 37 patients with advanced multi-morbidity and 17 family carers. This subgroup had a mean age of 76 years and 30% died during the study period. The main aim was to explore these people’s understanding of their health problems and their experiences of health and social care. (164) Patients with cancer often had a key professional or coordinated care from their general practice. In contrast, people with multiple advanced illnesses and their carers described the ongoing challenges of having to navigate multiple care systems, services and professionals. Polypharmacy and frequent medication changes compounded their problems and were already well described. (165) The most striking findings from this

study were the impact of the understanding people had of their health problems and the coping strategies many adopted to make sense of their experiences of illness, treatment and care. The dominant understanding of progressively, deteriorating health was one of being ‘old rather than ill’. This meant that people focused on living as well as they could in the present, tried to maintain autonomy and independence by not asking for or accepting services, and did not consider planning ahead. Even in the context of declining health and increasingly frequent episodes of acute deterioration, people often chose not to think about the patient’s risk of dying and they associated palliative care with imminent death which meant it had no relevance to their perceived needs or circumstances. General practitioners described a reactive approach to the care of patients who chose not to ‘*bother the practice unless they had a problem*’ and were not identifying people with an uncertain prognosis for their palliative care register even though they were not surprised to learn of the patient’s death.

*‘I personally don’t want anybody to come in because we cope ourselves and the way we cope is because we cooperate with one another you know.’* (Carer of P2—female, 76: heart failure, renal failure, diabetes)

*‘I think I’d rather be positive. I think I’m not going to get worse.’*  
(P5, female, 66: liver failure, diabetes, heart disease)

*‘I can’t say I was altogether surprised. He did have a pretty extensive vascular history. He’s probably one of those patients who quite commonly slip through the net when it comes to palliative care needs.’*  
(GP of P32 – male, 75: mitral valve disease, heart failure, peripheral vascular disease)

Delivering better care for the increasing numbers of people living and dying with multiple advanced conditions poses major challenges for health and social care systems across the economically developed world. (127) Specialist services and clinical guidelines still focus on optimal management of single diseases and often neglect wider social determinants of health. (165) (166) Primary care services have been busy addressing targets for health promotion and self-management that seek to maintain the well-being of people living with long term conditions and avoid hospitalisation. There is a pressing need to face the challenges of providing coordinated, generalist care for people with multimorbidity. (90) (167) (168) This includes being able to recognise when people might benefit from a holistic



supportive and palliative care approach to care, planning for the management of episodes of acute deterioration, and continuity of care for people whose health is declining. (77) Jerant has contended that only treatment intent distinguishes palliative care from other forms of medical care. (169) Most current medical care seeks to prevent death. By contrast, in palliative care, illness is treated to maintain or slow the rate of decline in quality of life. This type of holistic, general care is widely applicable and acknowledges the prolonged process of nearing death faced by many older patients who have chronic illnesses. It takes account of the wide variation in the point in time at which patients, families, and professionals perceive that death is approaching. He proposes a 'TLC' model of care for older people:

- Timely and Team orientated – proactive care delivered by a broad multidisciplinary team and diverse services.
- Longitudinal – palliative measures integrated with appropriate illness-focused treatments that evolve over time.
- Collaborative and comprehensive – care delivery and planning involving the patient, those close to them, and any professionals, services or community support able to help with holistic care needs.

Like the hospital patients we identified in the SPICT screening study described above, most people with multimorbidity interviewed for this study had a strong desire to maintain 'normality' for as long as possible. Talking about death or planning for dying was not part of that perspective. Even among patients with cancer attending a Scottish oncology service, many wanted honesty from their health care professionals but also preferred a degree of 'prognostic ambiguity' which allowed them to retain hope and live well in the present. (170) Older people in poor health tend to be particularly concerned about loss of autonomy and independence. (171) While death was an acknowledged reality for frail older people, it was not at the forefront of their concerns. People living with long term organ failure conditions worried more about having another acute exacerbation than a potentially fatal outcome. (172) The challenge here is how to implement effective approaches to care continuity and coordination that will support people who have advanced illnesses and deteriorating health to live well with inherent uncertainty while engaging with planning for what are inevitable episodes of deterioration that may or may not end in

the person's death. (173) An important first step is for everyone to accept and acknowledge openly the undeniable fact that when and how people deteriorate and die will always be unpredictable. Even when people are very close to death some uncertainty remains. (174) Secondly, talking about ways of managing uncertainty needs to become a core element of future care planning. Smith has proposed a framework aligned with patient priorities and consisting of three central tasks that clinicians can use to help patients and families manage uncertainty as part of future care planning. The first task is to explore people's expectations, be honest about the boundaries of our knowledge of what will happen, and normalise uncertainty about prognosis. The next is to talk about the emotional difficulties of living with uncertainty, before finally moving on to discuss what patients and families would find helpful as they manage the effect of uncertainty on their ability to live in the here and now. (91) An important trial of early palliative care in lung cancer showed that it was possible to plan for future episodes of deterioration with patients and families and talk about their values and priorities sensitively without disrupting what appeared to be a common view among patients and professionals that "thinking about dying" may not be helpful for people who are living with the demands of advanced illnesses by "living each day as it comes". (175) (176)

Managing uncertainty has long been a core aspect of general practice so primary care services should play a central role given that people in the UK spend about 90% of their last year of life at home or in another community care setting.(72) (177) A literature review of patient-professional communication about advance care planning for people with advanced cancer looked for best practice recommendations that could help those with other life-limiting conditions and suggested that the optimal context for future care and end-of-life discussions was within a trusting, long-term relationship that offered open and repeated negotiations around patients' preferences for information. (178) However, advance care planning alone is not the answer because it asks people to make projected decisions about future situations when their mental and/or physical health will be much poorer. An American interview study with older people elicited barriers to thinking about planning, discussion with family and friends, discussion with professionals, and documentation of an advance

directive. The most prevalent barrier at all stages was a perception that planning ahead in this way was irrelevant because these people perceived themselves as still “too healthy”, even though close to 70% reported having fair to poor health. (179)

Anticipatory care planning offers a more flexible alternative approach that is more grounded in people’s current reality. Anticipatory care plans are of particular value in guiding the management of episodes of acute deterioration and should be tailored to individual clinical and personal circumstances and regularly updated. A structured, anticipatory care planning intervention in the north of Scotland, based in primary care, was widely acceptable to patients, families and professionals and effective in reducing hospital admissions among frail older people. (180) Introduction of an electronic, Key Information Summary (KIS) for general practitioners throughout Scotland to record anticipatory care plans for any patient at risk of deteriorating has led to a marked increase in the number of people with advanced conditions that have such care plans. No direct association between the KIS and ‘palliative care’ has made it widely applicable and much more acceptable to professionals and patients than its predecessor, the electronic palliative care summary. (181) The KIS provides the necessary infrastructure for recording and sharing information between primary and secondary care and with out-of-hours services. A well-established, electronic record system in London is making a significant contribution to improvements in care coordination for people with declining health. It can be updated and viewed by a range of professionals and services and has a clear and accessible name – Coordinate My Care. (182)

Experiences and expertise gained from over ten years of research, the growing evidence base supporting integrated supportive and palliative care, and the benefits of the Scottish Key Information Summary were the basis for designing a pilot trial of a future care planning intervention for people with advanced heart disease being discharged home after an unplanned hospital admission. This is my final paper.

## **7. Anticipatory care planning with people with advanced heart disease: a pilot randomised controlled trial. (Paper 6)**

*‘Talk, Plan, Live’*

Dying Matters Collaborative

After ten years, I turned my attention back to the patient group that first prompted my research into how care could be improved and services developed to respond more effectively to people’s individual illness journeys and needs. I began with two studies involving people who had advanced heart failure. Even then, we recognised that many people were excluded from the structured support and care coordination offered to patients with left ventricular dysfunction by virtue of having other types of heart failure, ischaemic heart disease or multimorbidity. Future care planning provides a framework for discussing a range of problems with many more patients living with advanced heart disease and their families. This approach can be introduced much earlier needs to start well in advance of ‘end-of-life’ care. (24) I developed an integrated model of future care planning for people with advanced heart disease that brings together advance care planning and anticipatory care planning and updates the Framework published in my 2009 paper. (34)

Working with a cardiologist who has a special interest in advanced heart disease and palliative care, together we went on to design a pilot, stepped-randomised future care planning trial. (183) The trial intervention included and addressed what we know to be key components of an effective, integrated palliative care approach:

- Use clinical indicators to identify people with deteriorating health.
- Offer accessible patient information about future care planning.
- Integrate optimal illness-focused management with other palliative measures directed at quality of life.
- Use effective communication approaches to open conversations about the future, what matters to patients and families and managing uncertainty.
- Agree individualised anticipatory care plans for managing acute episodes of deteriorating health.
- Discuss continuity of care and the benefits of an anticipatory care plan recording key shared decisions within a Key Information Summary.

- Offer information about advance care planning relating to nominating a power of attorney and making decisions about CPR and implantable devices.
- Support people to engage with future care planning discussions within a longitudinal relationship with a specialist heart nurse able to offer open and flexible responses to patient and family preferences for information.
- Liaise with the patient's general practitioner and support the primary care team's central role in coordinating care of people with advanced multimorbidity.

Randomised controlled trials in palliative care are notoriously challenging to design and implement. (184) We followed the Medical Research Council guidance for trials of complex interventions and designed a mixed-methods, Phase I and Phase II pilot randomised trial. (185) In addition, we drew on methodology used to develop complex care interventions for people with dementia and the holistic management of breathlessness. (186) (187) Mixed-methods approaches to trial design enable better understanding of whether and how an intervention works (or does not work) and inform the design of subsequent studies. (45) The Phase I study reported in my sixth paper enabled us to refine the study design and explore important aspects of feasibility and acceptability with patients, carer and key professionals. (183) A social scientist facilitated focus group discussions with 15 patients and carers from two local support groups and interviewed a diverse sample of eleven health professionals. The interviews and focus groups were guided by a flowchart of the proposed intervention and a patient-held 'Thinking ahead' guide based on the one I had written and published with my third paper. (49) The Phase II trial consisted of a stepped intervention where eligible patients were randomised to either early intervention (before or soon after discharge from hospital) or delayed intervention (12 weeks later). Recruited patients received a copy of my refined 'Thinking ahead' guide as part of the study information and a meeting was arranged for them and their main carer with the trial cardiologist and specialist heart nurse to talk about their heart problems and future care planning. I provided advanced communication training in talking about deteriorating health, shared

decision-making and managing uncertainty for the cardiologist and specialist nurse using evidence based approaches to communication about serious illness and patient-centred future care planning. (176) (188) (189) (190) (191) Central to these discussions is a 6-step approach and use of communication skills such as hypothetical questions, generalisation and linking hopes with concerns.

During the 12 week follow-up period, the patients and families could contact the specialist nurse by telephone and she visited them at 6 and 12 weeks to review their care plan and update the primary care team and hospital services. Quality of life, measured with a standardised questionnaire (EQ5D), was the primary outcome. (192) Patients and carers also completed questionnaires recording anxiety and distress (Kessler score). (193) Service use data including hospitalisations was recorded. Supplementary data about people's experiences came from qualitative interviews with a purposive sample of patients, carers and their general practitioners.

It was important to design an intervention that would be feasible and effective as part of routine clinical care. An unplanned hospital admission is a key clinical indicator for identification of people with declining health due to advanced heart disease so we chose this entry criterion. In order to complete the trial within a finite time frame and demonstrate that those recruited had advanced heart disease, we also set an additional eligibility criterion of a 12-month mortality risk of 20% or greater at the time of discharge using the GRACE score for patients with an acute coronary event or the EFFECT score for people with heart failure. (112) (115) An initial assessment by a cardiologist reassured patients, families and other professionals that treatment of their heart condition would be optimised. Knowing that busy general practitioners find guidance from hospital specialists helpful in identifying people for a palliative care approach and appreciate timely information with clearly defined actions, we decided to send the initial and reviewed future care plans to the practice by secure email in a format ready to be uploaded into the patient's Key Information Summary. (181)

Ongoing support for patients and families and a point of contact for professionals from the nurse specialist provided the necessary continuity of care over time.

The trial was completed in March 2015 having successfully recruited and randomised 50 patients with advanced heart disease and has been presented at the European Association for Palliative Care Conference and submitted for peer reviewed publication. The intervention increased power of attorney nomination, CPR decisions and anticipatory care plans. There was no increase in anxiety or distress (Kessler score - E 16.7 (7.0) v D 16.8 (7.3),  $p=0.94$ ). Quality of life remained stable twelve weeks after discharge (EQ5D – E 0.54 (0.29) v D 0.56 (0.24),  $p=0.86$ ). This is important given concerns that early palliative care might cause psychological harm by disrupting people's coping mechanisms. The intervention was in fact valued greatly by patients, carers and general practitioners although the numbers were too small and the period of follow-up too short to demonstrate any significant impact on hospitalisations or other service use outcomes. A larger, multi-centre trial is planned.

## **8. Conclusions: a 2020 vision for integrated palliative care.**

Health policy in Scotland and other parts of the UK aims to deliver person-centred care that respects the values and priorities of individuals, their families and communities. Promoting health and wellbeing are given prominence, but so too is the need for integrated care of an ageing population living with multimorbidity. (194) Alongside these aspirations, comes a growing recognition that death and dying are an inevitable part of life and good care of people with deteriorating health due to one or more advanced illnesses in all care settings is a core responsibility of all health and social care services working in partnership with local organisations. Making this a reality requires high quality research which can inform changes in the way services are configured in the future to ensure that we are able to deliver what we know matters to patients, families and professionals. This critical review has therefore highlighted the two major challenges facing palliative care in the 21st Century, namely how to introduce a holistic, quality of life focused approach earlier in the illness trajectory of all advanced conditions and how to integrate that approach with effective, well-coordinated, continuing care of people whose health will decline to death in uncertain and unpredictable ways.

My research over the past 10 years has focused on people with heart disease as a proxy for other types of organ failure and more importantly for multimorbidity. It was evident in my two initial research studies involving people with advanced heart failure (Paper 1 and Paper 2), in the advance care planning study with general practitioners (Paper 3), when we identified people with deteriorating health after an unplanned hospital admission using the SPICT tool (Paper 4) and in my study of the experiences of people living with multimorbidity (Paper 5) that patients, families and professionals continue to find talking openly about death and dying difficult despite widespread public awareness campaigns. (195) If earlier and more systematic patient identification (Paper 4) is to be of real value, we need to improve ‘prognostic awareness’ and promote future care planning as a widely accepted process of well-coordinated planning shared between primary and secondary care that is responsive to people’s priorities and



supports genuine shared decision-making over time. Our pilot trial of future care planning with people who have deteriorating health due to advanced heart disease (Paper 6) has shown that this is challenging but achievable.

It could be argued my six research studies were all conducted in one part of Scotland so might have limited generalisability. However, this work when seen in the context of the wider literature and the evidence base for effective supportive and palliative care is widely relevant. The research findings in my papers resonate with the work of many other researchers cited in this review. In particular, we have understood and clearly articulated the importance of helping people to live well with the uncertainties of declining health whilst also being supported to plan ahead for what might happen when an episode of deterioration happens. This is the way forward for future care planning and should replace the narrower concept of advance care planning in which people are expected to make concrete plans for dying too far in advance for those plans to be reliably meaningful, applicable or helpful. Professionals still have to balance their responsibilities to share information about deteriorating health and offer patients and families the benefits of anticipatory planning and care coordination while taking care not to damage people's abilities to maintain a sense of normality and retain their autonomy. Offering clear guidance on ways to communicate, share information sensitively and engage people in an ongoing process of future care planning helps professionals have good conversations with patients and families. Together they can then reach better shared decisions about the things that should be planned in advance, such as nominating a Power of Attorney in case a person loses capacity for decisions, and accept those things that might well remain uncertain until much later on, such as place of death or treatment and care options. Once professionals feel confident and competent in having these conversations, they can use resources like the Key Information Summary to document individualised, anticipatory care plans. If people at risk of deteriorating have an up to date Key Information Summary that means any professional or service caring for them will be able to access information about what care and treatment options have been discussed already and any plans or priorities that

have been agreed in the event of a sudden change in the person's health or circumstances.

To do this successfully of course requires timely, proactive identification of those at risk of further deterioration in their health and of dying. My major contribution to palliative care research and clinical practice in the UK and internationally over the past 10 years has been the development and validation of an instrument to do this, the supportive and palliative care indicators tool (SPICT). For that reason, I have devoted a substantial section of this review to discussing the rationale for a different approach to patient identification. I have explained why a new tool was needed and shown how I used a detailed understanding of the strengths and limitations of the five main methods of identifying people for palliative care assessment to develop the SPICT in collaboration with an international community of colleagues. I have shown why targeting our efforts towards trying to predict when an individual patient will die is not only futile but potentially harmful because it often delays a review of care priorities and makes patients, families and professionals focus on preparing for death instead of planning for future episodes of deterioration. In the SPICT, I advocate use of probabilistic predictions of risk that someone may deteriorate and die. I have combined this with readily identifiable signs that a person's health is declining such that interventions to address care needs, symptom control, information and future planning should be initiated. The guide on the designated SPICT website encourages professionals to use the tool to help them to judge when to make an assessment of unmet needs that may include sharing information about the person's health problems and talking about what might happen. Clinicians should consider symptom management using palliative care measures integrated with appropriate treatment of underlying illnesses, psychological and family carer support, practical help with daily tasks, companionship and spiritual care. For some people, labelling this person-centred, holistic care as 'palliative care' might be helpful but for many others it will be indistinguishable from good quality, continuing care delivered by multiple professionals and services. The success of the SPICT programme, which now has many partners around the world, is

testament to the acceptability and utility of the SPICT as a tool designed to support better palliative care in all care settings.

Successful completion of a pilot, randomised controlled trial of an integrated future care planning intervention has demonstrated the potential benefits of the approach to palliative care discussed in this review. This study demonstrated that it was possible to combine patient identification with optimal care of underlying health problems, holistic care and symptom control all supported by sensitive and effective conversations about future care planning based on people's understanding and expectations. Identifying people in secondary care and then promoting and enhancing care coordination in the community proved an effective model that merits further evaluation. Future research needs to build on this work in larger trials with other patient groups in multiple centres. A parallel programme of engagement with service users would ensure that the perspectives of patients, families and the wider community continue to inform our thinking in palliative care research and development. There are many people with advanced progressive, life-limiting conditions, frailty and multimorbidity who stand to benefit from such research and its application in clinical practice.

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## Living with advanced heart failure: a prospective, community based study of patients and their carers<sup>☆</sup>

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### Abstract

**Background:** Services for people with heart failure are under-developed. The perspectives of patients, their informal and professional carers should inform development of service models. **Aim:** To describe how patients and carers view health and social care in the last year of life. **Methods:** Qualitative, serial interviews at three monthly intervals with 20 patients (New York Heart Association Grade IV heart failure), their main informal carer, general practitioner and other key professionals in an urban, community setting in SE Scotland. These were tape-recorded, and analysed with the aid of the qualitative data analysis package NVivo and techniques of narrative analysis. **Results:** 112 interviews comprised; patients (50), informal carers (27), professionals (30), bereavement interviews (5). Patients with heart failure and their carers felt unsupported by services, and had little understanding of their condition, treatment aims or prognosis. Quality of life was severely compromised by physical limitations and psychological morbidity. Psychosocial care, patient and carer education, co-ordination of care between primary and secondary sectors and with social services was generally poor. Many patients had no access to a heart failure nurse specialist. A palliative care approach was rarely apparent. **Conclusions:** Patients with advanced heart failure may benefit from specific models of care with strategic planning across primary and secondary care, and involvement of health and social care services and specialist palliative care providers. Models of care, which focus on quality of life, symptom control, and psychosocial support for patients and their families while continuing active treatment, should be developed.

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**Keywords:** Heart failure; Quality of life; Community care; Patient views; Qualitative methods

### 1. Introduction

Improved survival of patients with coronary heart disease is contributing to an increasing elderly population with considerable mortality and morbidity from chronic heart failure [1,2]. New York Heart Association Grade IV heart

failure has a 50% annual mortality and a high risk of sudden death, a worse prognosis than many cancers [3].

Compared with other chronic conditions, heart failure patients have reported some of the worst physical and social problems [4]. A large, retrospective study of bereaved carers in the UK found that many patients experienced uncontrolled symptoms, low mood, and poor quality of life and had little understanding of their illness and its prognosis [5]. Many patients cope poorly with self-care and complex medication regimens [6]. Breathlessness, fatigue and poor mobility were common in patients attending a hospital heart failure clinic where physical problems were usually being addressed but only half of the patients' social/functional problems and a third of their psychological issues [7]. Relatives of heart

<sup>☆</sup> 'I'm alive but it's no life...'

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failure patients have said that severe uncontrolled symptoms were often present at the end of life [8].

The complexity of care, and the economic costs of hospitalisation for people with heart failure have led to the development and evaluation of various service models based in secondary care but primarily aimed at maintaining patients in the community. These multidisciplinary services have generally included patient and carer education, supervised medication titration, regular monitoring and some form of specialist nurse intervention [9–13]. Major end-points for all these services were reduced hospital admission rates, cost effectiveness and improved functional status.

The UK National Service Framework for coronary heart disease sets standards for the NHS in England and Wales. It advocates structured care through use of a general practice heart disease register and treatment protocols that are shared across the local care networks. There should be effective hospital discharge planning and referral to social services, and adoption of the WHO palliative care approach in end-stage disease [3]. In Scotland, the national guideline endorses a comprehensive education programme, exercise, closely monitored therapy and rapid access to professional help if symptoms deteriorate [14]. The European Task Force described a similar framework for heart failure care [15]. All have recommended further research to identify the most effective way of delivering the different components of heart failure care and the effectiveness of each of them.

The range of issues facing patients with advanced heart disease and their carers, during the last months of life, has not been evaluated prospectively in the UK. We have already reported the key differences we found between people dying of lung cancer and heart failure [16]. This paper provides a detailed patient/carer centred account of the changing and evolving physical, psychological, social, and spiritual and information needs of people with advanced heart failure, and explores patterns of service provision in relation to meeting those needs. A qualitative approach was used to gain access to people's perspectives about the issues that most concerned them. Qualitative research uses an in-depth approach that yields patient-centred, contextual data and allows an open exploration of potentially sensitive issues [17,18].

## 2. Methods

A prospective, longitudinal design, using interviews at 3-monthly intervals for up to 1 year with patients, their informal carers, general practitioners and other key professional carers identified by the patient, was important in providing concurrent accounts from patients, carers and professionals. Once the interviews had been completed, a focus group was convened to allow key health and social care professionals, and lay representatives to discuss issues raised by the interviews and options for service improvements. The local research ethics committee and the primary care and hospital trusts approved the study. Written consent

was obtained before the first interview and confirmed at subsequent interviews.

### 2.1. Participants and recruitment

Patients with New York Heart Association Grade IV heart failure were approached by their consultant cardiologist or geriatrician, and selected to reflect the demography of the condition in the local Health Board area using a sampling frame developed in consultation with local specialists. Purposive sampling ensured collection of data from a wide range of informants. Recruitment ceased when no new emergent themes were being generated from the interview data. If a patient agreed to allow their details to be passed to the research team, their general practitioner was asked to confirm suitability for inclusion. Suitable patients were telephoned by the researcher, and an interview arranged in the patient's home. Of the 35 patients identified, 26 wanted to participate. One died soon afterwards, 4 withdrew during recruitment and one was not recruited for sampling reasons.

Consequently, 20 patients were recruited; 11 men and nine women. Their mean age was 74 years (range 57–92). Eight lived alone, ischaemic heart disease was the commonest diagnosis, and 11 had significant co-morbidity. The 112 interviews comprised; 50 with patients, 27 with their informal carers, 30 with professionals, and 5 bereavement interviews; 8–12 weeks after the patient's death. Seven patients completed all four interviews. Six died (three suddenly) during the study. The remaining seven moved out of the area (2) became too ill (2) or wished to withdraw from the study after two interviews (3).

### 2.2. Interviews and focus group

An experienced social scientist (MK) conducted all the interviews over a 2-year period (1999–2001). Patients and carers were invited, in a non-directive manner, to talk about their main issues and concerns, to describe the care they were receiving from health and social services in primary and secondary care, and to consider whether their needs were being met. The general practitioners and other key professionals were interviewed by telephone or face to face, according to their preference, using a series of open questions.

The 16 participants who attended the focus group included key health professionals (from primary and secondary care), social care professionals, palliative care specialists, and representatives of patient and carer groups and from the non-statutory sector. A trained facilitator (TFB) presented the key findings from the analysis of the interviews, and chaired the discussion.

### 2.3. Data analysis

Data collection and analysis were concurrent to allow emergent themes to be fed back into the continuing data



collection. The focus group and the majority of the interviews were tape-recorded and transcribed in full. Field notes were made after each interview, in more detail where a participant did not wish to be tape-recorded. All the data was entered into the qualitative data analysis package NVivo. Two qualitative researchers (MK and AW) took primary responsibility for analysis, coding the data independently, and using a narrative analysis framework [19]. The multidisciplinary steering group members read key sections of the transcripts and met regularly to review the data and discuss the evolving themes with them.

### 3. Results

We found that people living with advanced heart failure described a pattern of progressive decline punctuated by episodes of acute deterioration and admission to hospital, growing dependence and an unpredictable terminal phase. We summarise the key themes in Table 1 and in the text below, concluding with a summary of the focus group discussion.

#### 3.1. Physical problems

Health professionals tried to address these but many patients had severe breathlessness, persistent oedema, extreme fatigue, poor exercise tolerance, sleep disturbance and anorexia. Breathlessness caused particular anxiety, with patients commonly experiencing feelings of panic, worse when alone.

'I slipped down the bed and oh the panic attacks I got, and I had to sit up. I could not get my breath. I felt, oh I cannot really, you cannot actually tell people.'—Patient 1.

There was considerable co-morbidity, from lung disease, arthritis, visual impairment and deafness, liver and renal problems and diabetes. Falls were common.

'The heart problem does not seem to be the thing that bothers us. The other illnesses are so obvious that her heart did not enter the equation.'—Carer 2.

Complex, changing medication regimens and the side effects of treatment, including urinary frequency, gout, leg cramps and itching, presented further problems.

'The sickness makes me feel lousy. I am taking that many tablets now and I do not know what is what reaction. You sort one thing out and it starts another.'—Patient 3.

The frustration felt by general practitioners that little could be done for these patients, apart from changing the medication, was often conveyed to patients and carers.

'The main issues in her care... I suppose monitoring her renal function and trying to improve her shortness of breath and her exercise tolerance, although it would appear we're fighting a bit of a losing battle just now.'—General practitioner 4.

Table 1  
Key issues raised by patients with advanced heart failure and their carers

Issue	Illustrative quotation
Managing the physical symptoms	'The weight has been coming back on again, and making me breathless. Yesterday I saw myself in the mirror and I was shocked at how ghastly I look now.'—Patient 14
Managing the treatments	'First they decided to cut the water tablets and that was disastrous. Therefore they put them back up again but it is a dangerous sort of tablet, it can affect your kidneys and everything.'—Patient 4 'The last time the doctor was here she was worried about my lungs, so she put me on another tablet. Yet another one! I have to watch my weight, and the liquids all the time now.'—Patient 15
Information about diagnosis/prognosis	'I find they vary a lot in how much they want to talk to you, but some of them are very good.'—Patient 7 'I do not have to read up on their things, I never ask any questions. I always thought if I don't know nothing I shall feel better.'—Patient 16
Frustration and progressive losses	'Frustration—oh yes!... I see her [his wife] doing things and it makes me feel guilty... I just cannot do it... I find it very, very hard at times.'—Patient 5 'I try not to mope, but I dream of doing ordinary things'—Patient 17 'I am not depressed... not really depressed... it is just a low feeling and it is not a happy feeling and you just never feel your life is worth anything'—Patient 14
Coping strategies	'It is not wonderful but I can cope with it, I am still at home, I am with my family. It is a good enough life, it is still worth living for me.'—Patient 2
Social isolation and carer stress	'There is just the two of us here all the time... on top of one another. So it is, it is hard.'—Patient 13
End of life care	'He will not get better and we do not know how long he has got'—Carer 6 'I hope I can finish my days here. I have got my will made and my son is happy. Everybody is going except me. I have got to go on for ever, eh?'—Patient 10 'I suppose I am expecting it to be something catastrophic, so planning and discussing it is not really an issue.'—GP 14

### 3.2. Psychosocial issues

Emotional and practical problems were just as pressing but less well recognised by professionals. Physical limitations led to considerable social restrictions for both patients and carers. Patients lacked confidence making them less likely to go out. They became experts in the logistics of their routine journeys, knowing the barriers such as hills they faced, where toilets were, and shops they could stop and pretend to look at. For some, the smallest household job required major planning. Satisfying roles and relationships were compromised, self-esteem declined and social isolation and dependency grew. Low mood and anxiety were prevalent among both patients and carers as they struggled with the daily grind of living with heart failure. A few were more able to cope, particularly if they had supportive family relationships or were able to hope that things would not get any worse. Humour, a determination not to be beaten, pragmatism and stoicism were all apparent, but often fragile, coping strategies. Feelings of uselessness or hopelessness were common. Some patients said their quality of life was so poor that they would welcome death. These feelings were often not admitted to close family for fear of causing distress.

'I think he probably needs a gun if you were a horse, they would shoot you'—Carer 6.

Perceived ageism emerged, with many patients and carers feeling they had been written off.

'I want to be treated like a human being, not a lump of flesh everyone is trying to get rid of'—Patient 3.

Few patients received social services, benefits advice or had contact with voluntary agencies. People described battling with a complex benefits system and being turned down. Some struggled with the loss of dignity they felt at having to accept assistance with bathing, a wheelchair or aids to daily living. Carers often said they did everything themselves and that their expertise was not recognised, particularly in hospital. They felt they had no choice about taking on the caring role and extra responsibilities in the relationship.

'I felt we should have had more back up... really I was just left with it. I do not know what would have happened if I had been ill too'—Carer 6.

Many carers seemed to see the reality of the situation when patients wanted to maintain the pretence of managing well. Those patients who did not have an informal carer faced much greater difficulties and anxieties.

### 3.3. Organisation of care and patient involvement

Most patients and carers described a professionally-led model of care not a partnership approach. Some patients

feared that professionals would take sanctions against them if they complained or were perceived as difficult.

'She did not say anything about the tablets, and neither did I, because I would not like them to think that I was doing their job, because that can put them off you.'—Patient 7.

Having a poor understanding of heart failure, its management and prognosis compounded this. Some people did prefer to leave decision-making to the professionals and a few actively avoided information. Others adopted a more active role in seeking information or taking responsibility for decisions. Some would alter their diuretics to enable them to go out or actively question doctors about their treatment. Patients and carers often spoke of feeling responsible for 'balancing and monitoring' the situation, suggesting that these words were often used by professionals in explaining treatment. This was particularly in relation to medication, weight and activity level. Many thought that they had no choice about taking all the medication, believing it would prolong life.

'You have got to look at it that that is what is keeping you alive, so you just swallow them'—Patient 8.

Some patients had built partnerships with key professionals. Those with good communication skills, who were able to convey a real interest in the wellbeing of patients and carers, were appreciated. The general practitioner was usually the main contact, and sometimes offered good practical and emotional support.

'There is time to discuss the whole situation; she reviews the medication and our feelings.'—Carer 9.

However, if the patient and carer were unsure about raising emotional or spiritual issues and the general practitioner waited for cues, these areas remained neglected.

'I do see emotional and spiritual needs as part of my job but we do not tend to talk about them'—General practitioner 10.

Others complained that their general practitioner did not act quickly enough to prevent hospital admission, or found them unapproachable, or unable to give helpful advice about managing their condition. Continuity of care was important. Seeing different doctors at each hospital appointment caused particular dissatisfaction.

'Well the thing is that you wait all that time, and then do not always see Dr X, but one of his assistants, and they do not really know much about your case.'—Patient 11.

Patients often described negative experiences of hospital admission. Poorly co-ordinated care, lack of privacy and

dignity, and noisy and hectic wards allowed little time for personalised care.

‘They are so busy on those wards. A nurse would say I shall be your nurse for the today, and then I would never see her again.’—Patient 12.

Few patients had contact with a heart failure nurse specialist. For those who did, home visits allowed more time than a clinic appointment, and the nurse was able to give comprehensive advice about managing medication, day-to-day care and accessing benefits and aids in addition to offering psychosocial support. However, some general practitioners were ambivalent, wanting the specialist nurse to act more as a resource for the primary care team.

### 3.4. End of life issues

Although many had experienced ‘brushes with death’, few patients had discussed their preferred place of death or wishes for end of life care with professionals. Most patients thought about dying in the context of ageing. Many had made plans with relatives for their funerals and arrangements about money and property. The uncertainty of the prognosis, and lack of an opportunity to discuss it, made it difficult for patients and carers to know how imminent death would be, although there was awareness of being ‘really ill’.

‘Sometimes I am afraid in the morning to go in... he is fading away before my eyes. It could be another year or two or it could be another week or two, it could be tomorrow. I do not know.’—Carer 6.

A final admission to hospital was as likely to be due to a non-cardiac condition or increasing care needs beyond the capacity of informal carers and community services to cope. Once admitted, insensitive communication caused much distress.

‘They just told us they had a plan. They said, we have a plan that if she arrests we will not be resuscitating her. Just as if it was nothing. It was terrible’—Daughter of Patient 7.

Community specialist palliative care services were not involved. One patient saw a hospital palliative care nurse specialist, but only the day before she died.

### 3.5. Focus group

The focus group discussed the key findings from the interviews. The participants agreed that the lack of good individualised information, written and verbal, was a key but complex issue. Professionals had difficulty finding the right language to explain heart failure and its prognosis.

‘If you use the words ‘heart failure’ people muddle it up with heart attack and there is a danger of immediately frightening them although you do want to explain the seriousness of it. If you say the heart muscle is weakened or damaged they say ‘I expected to have a slightly weak heart’ and you have actually underplayed it.’—Consultant Geriatrician.

A range of models of care was seen as necessary to meet the different needs of individual patients and carers. Home visiting was considered an essential component, if information, psychosocial and spiritual needs is to be addressed effectively. Better co-ordinated services in hospital and community and improved communication between them would make a significant difference. Where heart failure nurse specialist services should be based was debated, although the needs and concerns they address were undisputed. Extending the role of specialist palliative care services, increasing people’s choice about place of death, and adequate respite care were seen as important. Access to benefits could be improved through greater awareness of prognosis and clear eligibility criteria in advanced disease.

## 4. Discussion

Until recently much of the focus for research and service development has been on medication to reduce mortality, and interventions to prevent frequent hospitalisation. Our study suggests that patients and carers want a more holistic approach to care with service providers taking account of psychosocial, spiritual, information and family needs. We confirmed that quality of life decreases as NYHA functional class worsens, but that it is not always directly related to the patient’s physical status [20]. The psychosocial problems that dominated the life of many of these heart failure patients are common to those with other chronic diseases [21].

Our participants, like most people with heart failure were elderly and many had significant co-morbidity. A medical model targeting a single disease is unlikely to address the spectrum of needs they described [2,22]. Primary care can be the best setting for chronically ill people, provided that their management is proactive, co-ordinated and integrates health and social care [22]. Shared care protocols developed with general practitioners, and structured monitoring of medication, combined with rapid access to specialist advice in a heart failure clinic can help to optimise diagnosis and treatment [23]. Specialist heart failure nurses are seen as key professionals in a heart failure care network [24] but a shortage of specialist nurses in the area limited our ability to assess their impact.

Hospital care will continue to be essential and the reasons for admission complex [25]. Early involvement of appropriate specialists and either structured discharge planning or



high quality endoflife care, using an integrated care pathway, should be available [26].

Participation in decision making, realistic goal setting and a sense of self worth contribute to maintenance of hope and involvement in life in those with advanced illnesses [27,28]. Improved quality of life, as defined by the patient and carer, is the goal as much as any reduction in mortality [29]. Our patients did not feel involved in decision making or goal-setting, and felt increasingly frustrated and worthless. That effective communication about diagnosis and prognosis is difficult was clear, and has many implications for end of life care planning. Judging prognosis is difficult but use of prognostic indicators in very advanced disease, and discussion about the patient's wishes can allow a shift in the goals of care [30,31]. It is interesting that most patients had planned their funerals, but not discussed their preferred place of care with any of the professionals. Professionals balance information giving with a desire to protect patients from losing hope [32]. Patient barriers to more open communication may include cognitive impairment or adoption of denial/disavowal as coping strategies, but it is clear that many patients and carers do want more information, provided it is given sensitively and in a way that addresses their individual concerns [33–35]. Communication skills training can equip professionals with the skills they need [32].

Palliative care specialists have expertise in communication skills, symptom control and management of the last days of life. Increased access to specialist palliative care advice in hospitals and the community should be available for patients with advanced cardiac disease but has resource implications and requires a cultural shift [36]. If the prognosis can be assessed as short, and a hospice/palliative care unit is acceptable to the patient and carer, inpatient care may also be appropriate. The Scottish Partnership for Palliative Care, a multi-professional organisation representing service providers from community, hospital and hospice sectors, is committed to widening access to specialist palliative care in Scotland [37].

Future research might usefully evaluate whether provision of psychosocial support for people with advanced cardiac failure improves their ability to cope and enhances quality of life. Rigorous assessment of heart failure services needs to include patient and carer centred outcomes and consider what types of specialist nurse interventions are most effective. End of life care in non-cancer patients merits much greater attention from service providers and researchers. The potential role of specialist palliative care services should be evaluated.

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# Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals

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## Abstract

The objective of this study was to evaluate the key components of services for people with advanced heart failure from multiple perspectives and recommend how care might be delivered in line with UK policies on long-term conditions, palliative and end-of-life care. Serial interviews were conducted over 2 years with patients, case-linked family carers and professionals ( $n = 162$ ); followed by four focus groups involving patients, carers and key professionals ( $n = 32$ ). There were 36 patients with advanced heart failure, 30 family carers and 62 professionals included in the study from a UK health region with various heart failure care models. Participants confirmed the value of a key health professional coordinating care, holistic assessment and regular monitoring. A lack of time and resources due to competing priorities in primary care, failure to respond to the fluctuations of a heart failure illness trajectory, concerns about the balance between direct care from specialist nurses or a more advisory role and difficulty in judging when to move towards palliative care hindered consistent access to proactive care. A heart failure care framework, with key stages and service responses, was developed. We conclude that patients with long-term conditions needing palliative care should be identified and managed using pragmatic criteria that include a proactive shift in care goals.

## Keywords

palliative care, heart failure, primary care, community services, end of life care

## Introduction

Heart failure is a major and increasing public health problem. Advances in medical management of coronary heart disease, hypertension and heart failure have improved survival, but morbidity is rising.<sup>1,2</sup> Patients are typically elderly and increasingly suffer from multiple co-morbidities. Evidence-based treatments and specialist nursing support mainly target

those with left ventricular systolic dysfunction.<sup>3,4</sup> Integrated clinical management, provision of information, and the psychological, social and family support that constitute good supportive and palliative care in heart disease remain suboptimal for many patients.<sup>4–6</sup> Care still tends to be reactive, with planning hindered by prognostic uncertainty.<sup>7,8</sup> In the UK, heart failure quality improvement initiatives recommending community-based approaches supported by specialist

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cardiology and palliative care services aim to decrease hospital admissions while optimizing service quality and sustainability.<sup>9-11</sup> Disease-specific care management is the second intervention level in the new programmes targeting people with long-term conditions. These initiatives also advocate supported self-management and intensive case management for high users of unplanned secondary care.<sup>12</sup> Recently published UK action plans on palliative and end-of-life care address provision of care in the last year of life regardless of diagnosis. Improving generalist palliative care and identifying when non-cancer patients including those with heart failure might benefit from a palliative care approach are particularly challenging.<sup>13,14</sup> It is important to integrate these different but overlapping strategies within a systematic approach to quality improvement and models of good practice are required.<sup>15</sup> The design and evaluation of heart failure management programmes should be improved. Data about the preferences of patients and carers is limited, and little is known about the views of primary care professionals even though they will have an increasingly important role.<sup>8,16</sup>

In this study, we extend previous work describing the complex needs of people with advanced heart failure to evaluate the key components of services currently provided in one health region and to recommend how they might be delivered more effectively from the perspectives of patients, family carers and key stakeholders.<sup>17</sup>

## Methods

We conducted serial qualitative interviews with patients with advanced heart failure, their family carers and key professionals, followed by four focus groups to give us a broad view of individual experiences and important aspects of regional heart failures services.

## Setting

Southeast Scotland is a mixed urban and rural area. The local heart failure service comprised a lead cardiologist, four heart failure nurse specialists, a volunteer support service, a charitably funded user forum and a multi-professional heart failure steering group that included primary care, medicine of the elderly and palliative care. It is broadly similar to heart failure services in many parts of the UK. The heart failure nursing service was available exclusively to patients with left ventricular systolic dysfunction following a hospital admission. Professionals could access specialist

palliative care services for any patients with complex palliative care needs using agreed referral criteria.

## Recruitment and sampling

Purposive sampling enabled recruitment of interview participants who reflected the local epidemiology of advanced heart failure (New York Heart Association [NYHA] Class III/IV) and were using the spectrum of services available. We recruited patients from general medical, cardiology and medicine of the elderly wards or clinics, and from primary care. Three multi-professional focus groups, and a focus group of patients and carers, discussed the interview data and added their own views about models of care. Focus group participants were recruited from the local heart failure users' forum and from professionals with a breadth of clinical and service management perspectives.

## Data generation and analysis

Each patient and family carer was interviewed up to three times: in hospital or shortly after discharge; 4-6 weeks later; and 4-6 months later. Key professionals identified by the patient were interviewed at the same intervals. This longitudinal approach enabled us to track changes in individual patient and carer circumstances and experiences of services over time. The concurrent interview triads of patient, family carer and professional were used to understand the context and complexities of care and to inform the focus group discussions. These groups considered the interview data and contributed their own perspectives as key informants to help us formulate specific recommendations about how services might be improved or remodelled.<sup>18</sup> The interview and focus group data were recorded, transcribed and analysed thematically with the aid of NVivo. Interview triads for individual cases were analysed longitudinally and constant comparison within and across cases ensured that the thematic analysis represented all perspectives.<sup>19</sup> Transcripts were coded to include anticipated and unforeseen themes. Patterns in the data were considered in relation to the broader conceptual literature about the experience and management of progressive chronic illness and have been interpreted with reference to the developing policy framework.<sup>5,10-14</sup>

## Results

Thirty patients with advanced heart failure (NYHA Class III/IV), 25 family carers and 41 professionals

yielded a total of 162 interviews. The 18 male and 17 female patients had a mean age of 76 years (range 48–91). Nine lived alone, 17 with a spouse or partner, two in sheltered housing and two in care homes. Most had multiple co-morbidities and experienced the numerous physical and psychosocial difficulties well documented in these patients and families.<sup>11</sup> Services with regular input or a key role were heart failure nurses (17), cardiologist (2), elderly medicine (5) and primary care (11); three patients had specialist palliative care involvement (Appendix I). Eight patients died during the study. The focus groups involved 21 professionals, 6 patients and 5 family carers.

### *Key features of effective patient-centred care in advanced heart failure*

Effective care was not restricted to a particular care setting and could be provided by a range of professionals according to the individual needs of patients and families and local service configurations (Box 1). Patients and families highly valued a key health professional in a supportive, continuing relationship with them who could coordinate and plan their care proactively, offer personalized information, and foster self-management. Professionals supported systematic, holistic assessment and regular monitoring of the patient's physical condition and medication as well as the information needs and psychosocial concerns of patient and carer.

The focus groups debated how best to target resources. They highlighted important tensions between providing better primary care services to the increasing numbers of elderly people with heart failure and multiple co-morbidities or expanding disease-specific specialist services of high quality but limited scope. The heart failure nurse specialists had concerns about whether non-specialists could provide optimal clinical management and patient/carer education. In contrast, primary care, elderly medicine and palliative care professionals thought specialists should offer education and support to other staff in primary and secondary care, and be available to advise on management of complex clinical problems instead of providing direct care to a limited patient caseload (Box 2).

### *Barriers to effective service provision*

We identified significant inequalities between those receiving well-managed care and the remainder who had reactive, episodic services and clarified the reasons

for this disparity. Effective primary care was significantly compromised by a lack of professional time and resources due to competing, target-driven priorities and limited input from district nurses. Difficulty recognizing and responding to the distinctive features of the heart failure illness trajectory with its acute episodes of deterioration and periodic improvements could mean out of hours services and community social services did not address a patient's current needs. Managing multiple co-morbidities was challenging, and social carers sometimes lacked support and education (Box 2).

Prognostic uncertainty hindered effective advance care planning. Some professionals found it hard to recognize triggers when the goals of care should be changed from disease focused management to a more palliative approach and worried about destroying hope if they raised end-of-life issues before the patient was clearly dying. However, patients who knew they had advanced heart disease often seemed to cope well with this information and professionals who were more open endorsed this approach. A lack of understanding about the advisory role of community palliative care nurse specialists and the association of hospices with dying made some people reluctant to accept these services (Box 3).

### *Delivering more effective services to people with advanced heart failure*

Working with the spectrum of participants who contributed to the interviews and focus groups enabled us to identify key areas for service improvement and relate these to published recommendations. Consensus-based criteria were thought to be helpful in enabling professionals to recognize when a palliative care approach to care that focuses on quality of life as much as a reduction in morbidity has become appropriate. Services for these patients would then be based not on restrictive prognostic judgements but be coordinated using an integrated approach to care planning that takes account of a fluctuating, organ failure illness trajectory. Community-based programmes for long-term conditions, including heart failure, need to include a framework that ensures regular review along with a shift in care goals and the services provided as the patient moves from chronic disease management to a supportive and palliative care phase, then to terminal care (Appendix II and Figure 1).

## **Discussion**

This study integrates patient and carer perspectives with those of key professionals to both confirm core



**Box 1. Key components of effective heart failure services**

- A key health professional to coordinate care, provide personalized information and support self-management.
- Managed care using primary care registers/databases to organise and monitor service provision; electronic prompts for review dates.
- A patient-held management plan including an advance care plan to be drawn up and reviewed by the key professional, patient and carer.
- Holistic assessment and regular monitoring of the patient's physical condition, functional ability, psychological and social needs.
- Implementation of clinical guidelines, disease protocols and care pathways for heart failure management, palliative and end of life care; access to specialist advice/assessment.
- Integrated care of patients with multiple co-morbidities; including medicines management.
- Identification of patients with palliative care needs and transition to supportive and palliative care as the illness progresses.
- Out of hours care planning: information and self-management strategies for patients and carers, anticipatory care planning, use of special notes to out-of-hours services including resuscitation status.
- Regular assessment and review of carer needs, including respite care and bereavement support.
- Joint health and social care planning for personal care and prompt provision of equipment and adaptations; assistance in applying for benefits.
- Access to allied health professionals such as pharmacists, dieticians, physiotherapists and occupational therapists.
- Information about voluntary sector support services (user groups, social support and carer support services) and educational resources.

**Box 2****Specialist services versus primary care:**

*'The majority of district nurses don't go in like we do to educate patients on self-management. They would need training on how to interpret the electrolyte results, on how to manage all the cardiac drugs and that's where the specialism comes in.'*

(Heart failure nurse specialist, Focus Group 1)

*'I don't think a specialist led model of care can ever be sustainable. It's this problem of having four different nurse specialists or four different consultants all dealing with different aspects... it always falls to pieces... what is needed is enough generalist resource to actually deliver care properly.'*

(Palliative care consultant, Focus group 2)

*'The whole point of the long term condition stuff is that more people are going to be encouraged to self manage... it can't come from specialist nurses. You can't create enough specialists in all the different areas. So I see it all coming back to the GP practice, which would include the district nurses, the practice nurses, whoever.'*

(GP, Focus Group 1)

**Barriers to delivery of effective heart failure services:**

*'It is not a priority on lots of people's minds. It is an afterthought, it is when they are knackered, they have got the other diagnoses and then oh – heart failure is there as well.'* (GP, Focus Group 1)

*'We're not seeing these types of patients until they have a nursing need. If they're requiring dressings and assessment of wounds, then we'd be involved.'*

(District nurse, Focus group 2)

*'There were 3 or 4 people who all said the same thing – that when they phoned (NHS 24) as a heart failure patient with an acute episode, they knew that all they needed was just that intravenous stuff that sorted it out... but by the time they had come off the phone from the NHS 24 who called 999 and made a fuss, they were terrified.'*

(Voluntary sector worker, Focus Group 3)

*'Last week we had a new one (social services carer) and when she came in she said "for a shower" and I said "well I'll not have a shower the day I'm going for a walk". So she said "my sheet doesn't say anything about going for a walk, it says getting dressed and showered."*

(Patient 14, Interview 1)

*'I worry about going in and finding her on the floor... she's got a lot of things going on and the diabetes. I don't know if you up the insulin or down the insulin, or what you do with things like that, so I can't give advice.'*

(Social services carer, Patient 5)

elements of care and clarify significant barriers that will need to be addressed if the type of holistic, structured palliative cancer care that is becoming established in the community is to be extended to all

patients with a life-limiting illness. Countries with well-developed primary care services have the potential to deliver coordinated care for patients who have advanced long-term conditions given adequate

## Box 3

## Prognostic uncertainty and talking about dying:

*'If you'd have asked me two and half years ago if I thought she was going to be here this summer I would have said "no". That I think probably demonstrates why I would be more reticent about talking about this with somebody with heart failure than with somebody with cancer.'*  
(GP, Patient 25)

*'I think (palliative care) is something that we do very badly because we like to make them feel better and ones who aren't getting better, I think it takes us a while for that penny to drop, we don't switch very well into palliative mode.'* (Cardiologist 1)

*'My doctor once asked me if I was worried about dying. I said, 'I don't want to die but if I'm going to die I've no worries I'm not frightened of dying but I want to live.'*  
(Patient 12, Interview 1)

*'It is difficult but increasingly I've talked about it with patients much more directly than I ever did before, partly because of my own growing concern ... that we don't talk adequately with patients about it and secondly I guess a growing confidence on my part that I can discuss it and that I can find the words.'*  
(Cardiologist 2)

*'The nurse comes from the hospice and she just talks to you. She has to come and see you because he is taking the morphine.'*  
(Carer 23, Interview 1)

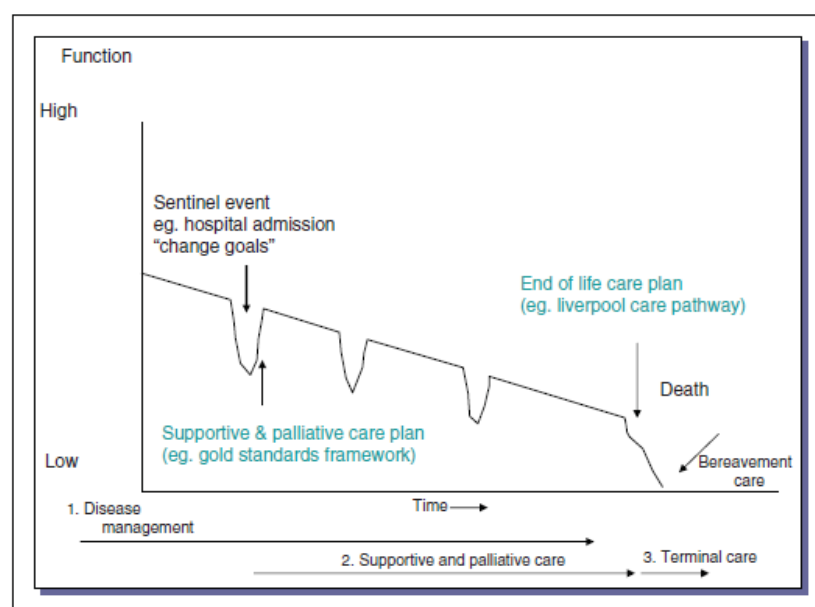


Figure 1. Three stages in progressive heart failure.

resources, organizational structures and specialist support. General practice registers of palliative care patients and regular multidisciplinary review will be implemented throughout the UK, and tools to enhance care coordination such as the Gold Standards Framework are being promoted widely for palliative care patients regardless of diagnosis.<sup>13,14,20</sup>

However, identifying when patients with organ failure type illnesses are at the stage in their illness trajectory where 'supportive and palliative care' should be

introduced is a particular challenge. Many older people with advanced illnesses will die relatively suddenly after a long period of fluctuating poor health.<sup>7,21</sup> Providing accurate prognostic data for 6–12 month mortality in an individual patient with advanced heart failure is nearly impossible.<sup>22</sup> Using pragmatic criteria to identify patients with advanced heart failure who might benefit from a palliative care approach could help address the restrictions of 'prognostic paralysis'.<sup>23</sup> The Gold Standards Framework suggests criteria

including professional judgement that this patient is ill enough for death in the next 12 months not to be a surprise, a hospital admission or referral for worsening heart failure, and poor performance status due to heart disease or co-morbidities indicating greater health and social care needs.<sup>20</sup> Deterioration in performance status that cannot be reversed is an important indicator.<sup>24</sup>

Clinical guidelines and good practice recommendations have been based on a single disease paradigm and the emerging models of care for older people with multi-morbidity in the community need to address this.<sup>12,25-27</sup> Patients should receive ongoing treatment and management of any acute episodes that meets best practice clinical guidelines for each of their illnesses but which also takes their overall health, goals and preferences into account. Life-limiting illness progressively changes the goals of care. The risk-benefit ratio of treatments alters and regular review is essential.<sup>28</sup> This will involve looking at how a range of specialist services can best support in-hours and out-of-hours primary care with education, telephone advice or assessment home visits and brief interventions including hospital or hospice outpatient review or admission. Integrated, multi-disciplinary care with good liaison between community, hospital and specialist palliative care services has improved cancer care and could be extended to other diagnostic groups as suggested previously.<sup>8</sup> Strict adherence to evidence-based protocols that escalated heart failure treatment in response to disease progression hindered a shift in care goals and exploration of patient choice.<sup>29</sup> A better principle of quality improvement might be less variation in prescribing between clinicians combined with a more individualized approach to patients.<sup>30</sup>

Interventions that help people navigate changing life circumstances, deal with uncertainty and retain a sense of control can help maintain hope.<sup>31</sup> Consensus guidelines for discussing end-of-life issues and shared decision making are helpful but the experiential education programmes that have improved communication in cancer care need to be available to clinicians caring for people with other life-limiting illnesses.<sup>13,32,33</sup>

### *Strengths and weaknesses of the study*

Longitudinal analysis of interview triads combined with cross-sectional analysis of interviews at specific stages allowed access to patient and family carer experiences as they negotiated a range of services and provided a broad, contextualized understanding of care in advanced chronic heart failure.<sup>18</sup> Professionals from primary care and specialist services contributed key information and insights about the barriers to

delivering better and more accessible care, and used the focus groups to discuss how services might be developed particularly in primary care.

The study took place in one geographical area, where services for people with heart failure are relatively well developed. Aspects of Scottish health and social care policy and service provision differ from those in other parts of the UK. While the setting encompassed a wide range of socioeconomic conditions, there was little variation in terms of ethnicity, so it was not possible to recruit any patients from minority ethnic groups.

### *Future research*

Interventions delivering managed care to practice populations with heart failure and other illnesses identified and reviewed using pragmatic clinical criteria such as those generated by this study should be evaluated (Appendix II). Individualized information and access to ongoing support have been identified as key patient outcomes.<sup>34</sup>

### *Conclusions*

A community-based approach has the potential to deliver high-quality palliative and end-of-life care to the growing number of elderly people with all types of heart failure and other advanced long-term conditions. In the UK, this is starting to be organized by GP practices adapting systems initially established for cancer patients, but the different illness trajectories and needs of non-cancer patients and those with multi-morbidity have to be addressed. Adequate resources particularly in primary care, services that respond flexibly to changing needs and care pathways that aid earlier identification, assessment and care planning for the patient with advanced heart failure and their family in need of supportive, palliative and terminal care are required.

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Appendix I. Characteristics of study participants

Participant	Age	Gender	Dep cat <sup>1</sup>	Co-morbidity	Lives with	Number of Interviews Patient Carer Professional	Models of Care
P01	75	M	3	diabetes, renal failure, cataracts	alone	2 0 3	Elderly medicine
P02	80	F	4	renal failure, depression	shelter housing	1 1 1	Elderly medicine
P03	64	F	4	diabetes, leg ulcers, COPD, renal failure	spouse	2 2 2	Elderly medicine
P04	85	M	5	epilepsy, hypertension, hiatus hernia	spouse	3 3 3	Elderly medicine Primary Care
P05	79	F	2	diabetes, hypertension	alone	3 3 3	Heart Failure Nurse
P06	78	F	5	deafness	alone	2 1 2	Heart Failure Nurse
P07	72	M	6	COPD	spouse	3 3 3	Palliative Care
P08	70	F	1	asthma, hypertension	spouse	3 3 1	Heart Failure Nurse Cardiologist
P09	73	F	2	TIA's	spouse	3 3 1	Primary Care Heart Failure Nurse
P10	86	M	6	CVA, UTIs	alone	3 3 2	Heart Failure Nurse
P11	86	M	5	diabetes, gout prostate cancer	spouse	3 3 1	Primary Care
P12	75	F	4	asthma, hypertension	alone	3 3 3	Heart Failure Nurse
P13	82	F	3	diabetes, renal failure, hypertension, anaemia	alone	3 0 0	Primary Care
P14	81	M	3	Parkinson's, arthritis, peptic ulcer	spouse	3 3 2	Heart Failure Nurse, Primary Care
P15	81	M	5	haemolytic anaemia, prostate cancer	alone	3 2 1	Heart Failure Nurse
P16	78	M	6	pulmonary embolism, COPD	alone	1 0 2	Heart Failure Nurse Palliative Care
P17	88	F	3	depression, arthritis, diabetes, hypertension	alone	2 1 0	

P18	91	M	4	prostate cancer, arthritis	partner	2	1	1	Elderly medicine, Primary Care
P19	87	F	1	arthritis	Nursing home	1	0	1	Heart Failure Nurse, Primary Care
P20	80	M	5	COPD, CVA, depression, renal failure	spouse	2	2	3	Heart Failure Nurse Nursing Home
P21	86	M	5	diabetes, renal failure, hypertension, polymyalgia	spouse	2	2	1	Primary Care
P22	56	M	5	peptic ulcer; hypertension	spouse	2	1	1	Primary Care
P23	82	M	5	COPD, renal failure, TIAs, colon cancer	spouse	2	2	1	Heart Failure Nurse Palliative Care
P24	59	M	4	diabetes	spouse	2	2	2	Heart Failure Nurse, Primary Care
P25	45	F	3	diabetes, renal failure	spouse	2	2	2	Heart Failure Nurse, Primary Care
P26	73	M	3	hypertension	spouse	2	2	2	Heart Failure Nurse, Primary Care
P27	83	M	2	CVA, hypertension	care home	1	0	2	Primary Care
P28	85	M	2	interstitial lung disease, renal failure	spouse	1	1	1	Heart Failure Nurse Residential Care
P29	83	M	5	Asthma, CVA, COPD, anxiety	shelter housing	1	0	0	Primary Care
P30	48	F	3	Asthma	spouse	1			Cardiologist
Additional key informant interviews									Cardiologists
Subtotals						64	49	49	
Total number of interviews								162	

<sup>1</sup>Carstairs' Deprivation Index for Scottish Postcode Sectors 2001: 1 = most affluent 7 = most deprived (Carstairs V, Morris R. *Deprivation and Health in Scotland*. Aberdeen University Press, Aberdeen, 1991).

## Appendix II. A framework for coordinated care of people with heart failure

### Stage 1: Chronic disease management phase: (NYHA Classes I–III)

- **Performance status:** good; no advanced co-morbidities.\*
- **Goals of care:** active monitoring, evidence based treatment to prolong survival, symptom control, patient and carer education, supported self-management.
- **Information:** name of condition and what that means, course of the illness/treatment.
- **Primary care team:** coordinates regular monitoring and review using local protocols derived from national guidelines; practice register/database for chronic illness triggers and monitors service provision.
- **Hospital specialists** (cardiologists and/or geriatricians): diagnostic review, assessment and specialist treatment/advice for complex cases; specialist support to primary care team.
- **Heart failure nurse specialists:** short-term interventions to aid patient self-management; support, advice and education for the primary care team.

### Stage 2: Supportive and palliative care phase: (NYHA Classes III–IV)

- **Performance status:** deteriorating due to heart failure and/or advanced co-morbidities; disease specific prognostic indicators used as an aid to professional judgement.<sup>†</sup>
- **Goals of care:** tertiary prevention; maintaining optimal symptom control and quality of life.
- **Information:** discuss changing condition, goals and preferences for future care; anticipatory care planning with patient and family.
- **Primary care team:** move patient to Supportive Palliative Care register; identify a key professional; ensure regular holistic, multidisciplinary assessment of patient and carer health and social care needs; treatment and medication review in consultation with hospital specialists; plan for acute crises including liaison with out-of-hours services.
- **Hospital specialists:** assessment and specialist treatment review for complex cases; specialist support to primary care team; planned admission and rapid triage if hospital inpatient or outpatient care needed; coordinated discharge planning.
- **Heart failure nurse specialists:** specialist advice to primary care team on heart failure medicines management and monitoring; hospital/community liaison for patients needing secondary care.
- **Palliative care specialists:** support for primary care team and hospital specialists; specialist advice or short term interventions for symptom control, complex communication and advance care planning.

### Stage 3: Terminal care phase: (NYHA Class IV)<sup>‡</sup>

- **Performance status:** frail and largely bed bound despite maximal therapy; no reversible problems, or life threatening co-morbidity. Dying period may range from days to weeks; clinical indicators: renal impairment, hypotension/tachycardia, persistent oedema, anaemia, hyponatraemia.
- **Primary care team:** coordinate comprehensive health and social care package for patients who remain at home; plan for management of acute deteriorations; clarify resuscitation status; withdraw medication not for symptom control; carer support including bereavement care.
- **Hospital specialists/specialist nurses:** advice/management of treatment withdrawal (e.g. defibrillators); optimize end-of-life care of patients dying in hospital (integrated care pathway).
- **Palliative care specialists:** advice and support for end-of-life care in hospital and community; advice on complex symptom control in end-stage organ failure.

\*WHO performance status 0/1 or modified Karnofsky performance status 80–100.

†WHO performance status 2/3 or modified Karnofsky performance status 50–70.

‡WHO performance status 4 or modified Karnofsky performance status 40 or less.

# Advance care planning for cancer patients in primary care: a feasibility study

Kirsty Boyd, Bruce Mason, Marilyn Kendall, Stephen Barclay, David Chinn, Keri Thomas, Aziz Sheikh and Scott A Murray

## ABSTRACT

### Background

Advance care planning is being promoted as a central component of end-of-life policies in many developed countries, but there is concern that professionals find its implementation challenging.

### Aim

To assess the feasibility of implementing advance care planning in UK primary care.

### Design of study

Mixed methods evaluation of a pilot educational intervention.

### Setting

Four general practices in south-east Scotland.

### Method

Interviews with 20 GPs and eight community nurses before and after a practice-based workshop; this was followed by telephone interviews with nine other GPs with a special interest in palliative care from across the UK.

### Results

End-of-life care planning for patients typically starts as an urgent response to clear evidence of a short prognosis, and aims to achieve a 'good death'. Findings suggest that there were multiple barriers to earlier planning: prognostic uncertainty; limited collaboration with secondary care; a desire to maintain hope; and resistance to any kind of 'tick-box' approach. Following the workshop, participants' knowledge and skills were enhanced but there was little evidence of more proactive planning. GPs from other parts of the UK described confusion over terminology and were concerned about the difficulties of implementing inflexible, policy-driven care.

### Conclusion

A clear divide was found between UK policy directives and delivery of end-of-life care in the community that educational interventions targeting primary care professionals are unlikely to address. Advance care planning has the potential to promote autonomy and shared decision making about end-of-life care, but this will require a significant shift in attitudes.

### Keywords

advance care planning; cancer; palliative care; primary health care.

## INTRODUCTION

Advance care planning is viewed as an intrinsic component of end-of-life care programmes in many developed countries. In the US, advance directives were originally intended to allow people to record an advance refusal of invasive, life-prolonging interventions.<sup>1</sup> The limitations of this approach resulted in a progressive move internationally towards a broader process of advance care planning that also includes discussion of personal goals, wishes, and preferences about future care.<sup>2-4</sup> Programmes in the US and Australia that have adopted a regional strategy towards educating professionals, patients, and the general public about advance care planning have had some success.<sup>5,6</sup>

Proactive care planning is central to recent UK policies, and the expectation is that it will now be offered to all patients approaching the end of life.<sup>4,7</sup>

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Advance care planning is conceptualised as an ongoing process of discussion between an individual, who has the capacity to make healthcare decisions, and their care providers about future care when deterioration in the patient's condition can be anticipated. Thus it includes planning for loss of capacity to make decisions, and nomination of a healthcare proxy. Preferences and goals for treatment and future care (including place of care) are to be recorded and communicated to all professionals involved in care. The key underpinning values of this approach are patient choice and autonomy (Box 1).<sup>4,9</sup> Although patient participation in advance care planning is voluntary, it is being strongly advocated by the UK royal colleges, with a recommendation that GP practices demonstrate that it was offered to all their patients whose death could be anticipated.<sup>10,11</sup>

Communication between health professionals, patients, and families about end-of-life issues is often suboptimal, with health professionals tending to underestimate patient and carer information needs and overestimate their understanding and awareness.<sup>12</sup> The evidence suggests that most seriously ill patients want information about their diagnosis, but preferences about prognostic information are more variable, and family carers have different information needs as the patient deteriorates.<sup>13</sup>

When oncologists were able to discuss end-of-life issues with cancer outpatients and their families in a cohort study, those patients had less-intensive medical care near death, and family bereavement adjustment was also found to be better.<sup>14</sup> Similarly, an advance care planning process in care homes that promoted discussions about future care reduced inappropriate hospital admissions and mortality.<sup>15</sup> A nurse-led, advance care implementation process using a recommended advance care planning tool significantly increased home deaths for those patients in the intervention group who had cancer and a relatively short prognosis.<sup>16</sup> Some, but not all, cancer patients and their families in another advance care planning interview study welcomed an opportunity to discuss end-of-life care if the discussions were timed carefully and took account of individual coping strategies.<sup>17</sup> However, English GPs and community nurses often found it difficult to elicit patients' preferred place of death well in advance, and identified multiple constraints preventing them from discussing and eliciting patients' wishes.<sup>18</sup>

It seems that advanced care planning may prove helpful in managing some patients with cancer and people living in care homes. However, there has been little research assessing the impact of advance care planning with UK primary care professionals, even though they are to have a central role in offering it to larger numbers of people in the community.

## How this fits in

Advance care planning is currently a key element of end-of-life care policies in many countries. These policies direct professionals to identify patients in the last year of life, then discuss and document their future care preferences, with the aim of facilitating a 'good death' in line with those wishes. An evidence-based intensive educational workshop about advance care planning delivered in primary care increased clinicians' knowledge and skills, but had limited perceived impact on patient care. Multiple structural and professional barriers hinder implementation of advance care planning by primary care teams, particularly the tension between intuitive, personalised care and highly structured approaches. These will need to be addressed if advance care planning policies are to achieve the desired improvements in end-of-life care.

Therefore, this study set out to explore the views of GPs and community nurses in four Scottish practices about advance care planning for cancer patients; to evaluate their learning objectives; and to see if a tailored educational intervention that could be delivered at practices during continuing education sessions would encourage greater involvement in advance care planning.

## METHOD

### Sampling and recruitment of practices

Four diverse GP practices in south-east Scotland were recruited sequentially between July 2008 and March 2009 to provide a purposive sample representing

### Box 1. Advance care planning: policy definitions.<sup>a</sup>

Advance care planning is a voluntary process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included.

#### Suggested timing and context include:

- life-changing event (for example, a close bereavement)
- new diagnosis of a life-limiting illness
- indicators of a limited prognosis
- multiple hospital admissions
- admission to a care home

#### An advance care planning discussion might include:

- understanding of illness and prognosis
- the individual's concerns about his/her health and future care
- important values or personal goals for care
- preferences for types of care or treatment in the future
- preferred place of care
- advice on appointment of a proxy decision maker (health and/or financial)
- Documentation of a legally binding advance decision to refuse specific medical treatments
- Decisions about cardiopulmonary resuscitation

Table 1. Study participants.

	Initial interview	Workshop	3-month interview
Practice 1: four GPs, semi-rural, 3200 patients, 64% deprivation score* 2 or 3			
GP 1	✓	✓	✓
GP 2	✓	✓	✓
GP 3	✓	✓	✓
GP 4	✓	✓	✓
District nurse 1	✓	✓	✓
Practice nurse 1	✓	✓	✓
Practice nurse 2	✓	✓	✓
Practice 2: eight GPs, 8200 patients, urban, 71% deprivation score 1			
GP 5	✓	✓	✓
GP 6	✓	✓	✓
GP 7	✓	✓	✓
GP 8	✓	✓	✓
GP 9	✓	✓	✓
GP 10	✓	✓	✓
GP 11	✓	✓	✓
GP 12	✓	✓	✓
Practice nurse 3	✓	✓	✓
Practice 3: five GPs, 5000 patients, suburban, 40% deprivation score 5			
GP 13	✓	✓	✓
GP 14	✓	✓	✓
GP 15	✓	✓	✓
GP 16	✓	✓	✓
GP 17	✓	✓	✓
Practice nurse 4	✓	✓	✓
Practice nurse 5	✓	✓	✓
Practice 4: three GPs, 3000 patients, urban, older, 87% deprivation score 5			
GP 18	✓	✓	✓
GP 19	✓	✓	✓
GP 20	✓	✓	✓
District nurse 2	✓	✓	✓
Practice nurse 6	✓	✓	✓

\*Deprivation scores from Information Services Division Scotland: 1 = most deprived, 5 = least deprived.

different practice sizes, organisational structures, and populations served, in order to allow the intervention to be refined as the study progressed. The four practices were using the Gold Standards Framework Scotland 2005 tools, so already had registers of cancer patients and well-developed care-planning processes for those patients and families.<sup>19</sup> Details of the practices and the community professionals who participated in the study are summarised in Table 1. The primary care clinicians consented to individual interviews before and after the intervention, and also gave signed consent to participate in the workshops.

#### Refining and delivering the intervention

One researcher visited each practice to discuss how an advance care planning process might fit with existing working practices. The researcher then conducted face-to-face, semi-structured interviews lasting around 30 minutes with individual GPs, practice nurses, and district nurses to explore their current understanding of advance care planning and possible barriers to its use. Specific learning objectives for those clinicians were

elicited for inclusion in a tailored educational workshop given at that practice.

The intervention consisted of an afternoon workshop at each practice, delivered jointly by a palliative medicine consultant with expertise in postgraduate communication education, and a senior GP researcher. The workshop included discussion about advance care planning and its role in end-of-life care, a toolkit of resources for professionals and patients, and a sample advance care planning document based on the tool from the Gold Standards Framework Scotland, developed mainly for use in care homes (Copies of this document are available from the author on request.)<sup>20</sup>

Effective ways of discussing end-of-life issues with patients and families were explored through use of an interactive role-play interview using a participant-generated scenario. The scenario consisted of a series of key events that might trigger advance care planning. An internationally recognised, Australian consensus document on communicating prognosis and end-of-life decisions with patients was used as the theoretical basis for the communication education.<sup>21</sup> During the workshop, participants discussed ways of trying an advance care planning process with their own cancer patients.

#### Assessing the impact of the workshop and the generalisability of the findings

The researcher interviewed the community professionals again 3-months after the workshop. The post-intervention interviews looked at whether the workshop was considered effective, and if the primary care clinicians had changed their approach or attitudes to advance care planning.

Once the intervention study in all four practices was completed, telephone interviews were conducted with a purposive sample of nine Macmillan GP facilitators (GPs with a special interest in palliative care education) from other parts of the UK, to establish whether the findings in south-east Scotland were likely to be generalisable.

#### Data handling and analysis

The interviews were recorded, transcribed, and entered into NVivo™ (version 7) for thematic analysis, along with field notes taken by the researcher at each workshop. Regular discussion of the emerging findings among the project steering group with an established cancer service users' reference group linked to the project team, and with the two workshop leaders strengthened interpretation and led to modification of the advance care planning intervention and document in successive practices (Appendix 1). Although the workshops were broadly similar, discussion of issues of particular interest to

each practice was encouraged, and topics that had emerged in previous workshops were introduced. The study took place when major end-of-life policy initiatives were being implemented across the UK, so these were raised for discussion with participants in the four practices and with the GPs from across the UK who were interviewed by telephone. The impact of the current policy directives was also considered in data analysis. These discussions allowed the researchers to gain a broad range of perspectives on advance care planning and to establish whether the emerging themes were representative of more generally held views.

## RESULTS

Five practices were approached and all were keen to participate, but one could not do so in the time frame of the study. There was a high level of engagement in the interviews and workshops (Table 1). A total of 20 GPs and eight community nurses from four practices in south-east Scotland participated. It was clear from the first interviews and at the workshops that these primary care clinicians had limited understanding of advanced care planning as defined in UK policies and did not practise its main components in a structured way. Instead, they operated a very well-developed model of multidisciplinary care, which focused on ensuring that dying people with a short prognosis received optimal care in the community at the end of life.

### *GPs' understanding of advance care planning and their practice before the intervention*

The GPs and community nurses described components of advance care planning, but did not articulate these in a cohesive or consistent way. They reviewed their palliative cancer patients regularly, concentrating on practical aspects, such as completion of financial benefits forms, documenting cardiopulmonary resuscitation status, and organising care at home:

*'When I hear the words "advance care planning", I think that it puts a bit of pressure on that we're not doing things soon enough. It's normally quite obvious when somebody is now in the dying stages and we are trying to be more proactive, doing the DS1500 [benefits form] pretty early on ... and with our regular meetings we're all more aware what needs to be done and who is going to do it.'* (GP 2, practice 1, interview 1)

The absence of structured advance care planning processes did not mean the participants were failing to initiate proactive end-of-life care discussions. Indeed, they prized palliative care as one of the few remaining 'old fashioned' aspects of primary care, as much an art

as science, based on relationships, and something that should not be at risk of reduction to a checklist or form. These professionals believed that they were already providing the kind of individualised, personal care that policy makers and patients wanted:

*'I think what makes for really good successful palliative care is the relationship you develop between yourself, the patient, and their carers.'* (GP 8, practice 2, interview 1)

*'Yes, I suppose it's not very PC [politically correct] to say it's intuitive but I think it has to be because you're dealing with you know the very core sort of sentiments about life and death and that can't be too calculated or tick boxed.'* (GP 9, practice 2, interview 1)

*'Bringing up certain points like advanced care directives is very important but I don't think it should be done as part of a tick-box exercise ... almost like you're doing things for the sake of doing them. Whereas I think in good palliative care, you are trying to figure out the patient's wants and needs and their best interests.'* (GP 17, practice 3, interview 1)

### *'Planning for dying' rather than 'planning for living and dying' in primary care*

All the practices were operating a structured care model designed to ensure patients' last weeks of life and death were well managed. This consisted of a coordinated and often rapid response by the multidisciplinary team once it was clear that the patient would die soon. The most common trigger was discharge from hospital care once oncology treatment had ended. Before this, multiple factors hindered open discussion, particularly prognostic uncertainty, limited liaison with hospital services, and experiences of hospital staff focusing on the likely benefits of treatment even when the patient appeared to be deteriorating. Sometimes patients did provide a clear prompt to start end-of-life discussions. Persistent symptoms, including pain, were seen as 'opening the door' once they became impossible for the patient to ignore. Occasionally, a patient asked questions that indicated they were 'ready' to discuss their future care and end of life issues:

*'There is still a grey area where treatment is not going to cure you, but you are not actually about to die. Patients look for their cues and their leads from their hospital specialist. And if they are getting what I would perhaps think of as inappropriately positive messages from the hospital, it is then very hard for us to introduce the*



topic of, "But where would you like to die?" (GP 16, practice 2, interview 1)

*'If you're requiring more treatment and something to fix the pain that you're in it becomes almost easier to have that discussion as well.'* (GP 7, practice 1, interview 1)

#### **Barriers to change in end-of-life care planning**

The biggest barrier to initiating earlier conversations was a strongly expressed fear of destroying positive coping strategies. When asked to describe the key components of a conversation about end-of-life planning, these professionals almost always started with the preferred place of care at the end of life and worked backwards from that point. Formal advance care planning was perceived as 'planning for dying' too soon and in a way that did not take account of professional-patient relationships and individual patient needs. Discussing the place of death before the illness was more advanced, conflicted directly with promoting hope, maintaining normality, and letting patients enjoy as much of their remaining lives as possible:

*'He's got pancreatic carcinoma, inoperable, and he is palliative, but he's just been on a cruise and he's fine you know. It wouldn't be right to go in and constantly talk about death for him. I'm sure he will go downhill quite quickly, but at the moment he's enjoying life so that's great.'* (GP 11, practice 2, interview 1)

Expertise in end-of-life care was mostly considered to be something that could not be taught easily but would be gained with experience in practice. In the GP practices in this study, involvement in end-of-life care tended to be restricted to a small number of senior doctors and community nurses. Many of the younger doctors had little or no experience of end-of-life care in the community and were keen to receive more training. When a GP did raise end-of-life issues sensitively, patients appreciated it and the doctor's confidence increased:

*'I think it really just comes from experience and you know what you've learned through life and picked up.'* (District nurse 1, practice 1, interview 1)

*'One often gets a feeling of relief from the patient that somebody's prepared to open up that conversation and that if you do it in a sensitive way those patients who are not ready to have that conversation are able to say so.'* (GP 19, practice 4, interview 1)

#### **Implementing an advance care planning process in primary care**

Integrating any paper-based advance care planning documentation into computerised practice record systems will prove difficult. The written care plan that practices were asked to evaluate was perceived to be static, likely to lead to 'ticking boxes', and a duplication of other systems for recording and communicating patient information. During the project, a new patient-held guide to forward planning was generated, which could be used as an aid to discussing a patient's thoughts and goals. During the workshops, the participants discussed a standardised cancer patient scenario. They always chose to work on the communication challenges associated with the point where cancer treatment was no longer an option and the patient's prognosis was limited. This was consistent with their model of 'planning for dying' which meant that they needed to explore strategies for delivering bad news about the end of treatment before being able to move on to shared decision making about end-of-life care.

In the follow-up interviews and visits to practice meetings, a variable response to the intervention was found. The workshops were considered relevant and of practical educational value. Understanding of advance care planning had clearly increased, but there was limited evidence of a change in practice. One experienced district nurse reported being able to initiate end-of-life care conversations with a patient after the workshop. Four senior GPs described using the initial form as an aide-memoire when speaking with patients, but were ambivalent about its benefits. One GP had used the final patient-held final version of the form to aid advance care planning discussions with three people and thought it useful, but not for all patients:

*'I think certainly from the workshop I found it easier to lead the conversation ... before I wouldn't have had the confidence to have gone into the depth that I did, so it was very helpful.'* (District nurse 1, practice 1, interview 2)

*'I haven't used the form because I felt very uncomfortable using a form in what to me feels like a very intimate sort of conversation ... it's almost something where you don't want forms.'* (GP 12, practice 2, interview 2)

For the telephone survey of GPs with a special interest in palliative care education, nine Macmillan GP facilitators from England, Ireland, and other parts of Scotland were recruited. These doctors described how they were actively promoting regular review and care planning for palliative care patients in line with the Gold

Standards Framework Scotland, but were not practising or documenting an advance care planning process routinely in their own practices. Difficulties over terminology and confusion with related activities, like anticipatory care planning, were common. There were general concerns about formal processes being overly prescriptive and difficult to achieve in primary care:

*'We are doing a lot of planning but not necessarily formally. We certainly aren't using a lot of documentation or any specific crib sheets or pro-formas. What we are doing is a part of normal care, needing to have the conversations about the issues that are important. If you formalise it then it starts to feel false or pressured or we have to do it at a particular time, which has the potential to affect the natural patient-doctor relationship, or introduces time pressures that we just don't want.'*  
(Macmillan GP 5: palliative care educator)

## DISCUSSION

### Summary of main findings

This feasibility study explored current practice in end-of-life care for cancer patients in the community and found a well-established working model that differed significantly from recent national policies. The formal advance care planning policy approach and the current management of end-of-life care by these primary care teams share the common goal of 'planning well for dying' so as to ensure that patients receive high-quality care that is consistent with their wishes and values.

Although the study participants supported the general principles of advance care planning, namely respect for patient autonomy and provision of individualised information about prognosis and future care, they were very concerned about the dangers of an externally imposed and monitored system as a driver for improved care. Less-experienced clinicians were keen to engage in training that improved their abilities to discuss end-of-life issues. More open communication with patients about end-of-life issues was hindered by lack of information or conflicting information from secondary care.

Professionals strived to balance their responsibility to share appropriate information about the future in a timely manner, with maintaining positive coping strategies. For some patients, living well with cancer was seen as incompatible with frank discussions about the practicalities of dying until the illness was far advanced. The primary care professionals in this study often associated advance care planning with having to discuss the preferred place of death, and this difficulty was compounded by pressure on them to increase home deaths when they had serious doubts about whether this was a realistic option. The present

findings in south-east Scotland were replicated in a broader survey of some of the GPs who might have been expected to have adopted advance care planning in their own practices, but had not done so, thus suggesting that the findings of the present study are likely to have wider generalisability.

### Strengths and limitations of the study

This study provided a detailed analysis over time of how a diverse selection of primary care teams in Scotland manage their dying cancer patients, and generated a better understanding of the informal, but complex, interpersonal and organisational structures that underpin their current model of care. Repeated discussions with a series of practices allowed exploration of their views about how best to plan care in the last year of life, and identification of key barriers to changing practice in line with the new policies. The study sampled a diverse group of primary care professionals who evaluated the strengths and weaknesses of different approaches to planning for dying with the research team. Insights from the user group complemented professional perceptions in developing and evaluating the intervention. The telephone survey of GPs with a special interest in palliative care education clearly suggested that the study findings are not restricted to one part of the UK.

During the study, new policies in end-of-life care were being implemented across the UK and were not yet well established in south-east Scotland, so it is likely that understanding of advance care planning will continue to evolve. The study focused on one diagnostic group and setting: cancer patients were chosen for study as a readily identifiable group of dying patients in the community. Advance care planning may be more relevant to people at greater risk of losing capacity, such as those with early dementia or progressive neurological conditions; to people receiving life-prolonging treatments, such as renal dialysis; and to those living in care homes.<sup>22,23</sup> Nurses were under-represented among the study participants due to staff changes at the time of the study, but a recent study with English community nurses found similar barriers, including concerns about the bureaucratisation of end-of-life care planning.<sup>24</sup>

### Comparison with existing literature

Advance care planning at any stage of an advanced progressive illness requires open discussions about future deterioration, death, and dying, between patients, professionals, and family members, and this may be a greater barrier than the content of any advance care plan itself.<sup>25</sup> Clinician factors leading to ineffective advance care planning and medical decision making near the end of life are complex, and

can include responses to adverse emotional experiences, strongly held beliefs or attitudes, and communication skills deficits, such as blocking behaviour and 'jolly' patients along.<sup>26,27</sup> Physicians caring for cancer patients in the US have reported that they would not discuss end-of-life options with patients who are feeling well, but would wait for symptoms or the end of treatment.<sup>28</sup>

Patients and families have engaged with advance care planning to a variable extent, and barriers have been identified at each stage of the process: thinking about the future, discussion with family and friends or with a doctor, and completing the documentation. Seeing advance care planning as irrelevant to current personal circumstances was common.<sup>29</sup> Difficulty contemplating serious illness and fears about premature treatment withdrawal are important concerns to address if wider public engagement in advance care planning is to be achieved.<sup>1</sup>

The Association for Palliative Medicine of Great Britain and Ireland (APM) has supported the principles of advance care planning, but has expressed concern that the process might not remain voluntary if advance care planning were to become a health service outcome measure. APM has also emphasised that flexibility is important because patient and family views often evolve over time, for instance, regarding the place of death.<sup>30</sup>

Changing professional and public attitudes about end-of-life care to greater openness about death and acceptance of the limitations of curative medicine have been identified as crucial to the success of UK end-of-life care programmes.<sup>4,7,31</sup> Some cancer patients find that being open about their illness and a limited prognosis enhances communication in the family and a sense of control in end-of-life decisions; but other patients need to maintain a degree of ambiguity about their future to cope with the illness.<sup>32</sup> Maintaining hope in the face of any life-limiting illness is challenging, but forward planning can contribute positively if patients and families are supported to cope with uncertainty and are helped to focus on achievable personal goals.<sup>23,33</sup>

Advance care planning does not guarantee, however, that a patient's previously documented preferences will be realised, given the uncertainties of illness and medical care.<sup>2</sup> Nor does advance care planning lessen the responsibility of professionals to offer information, guidance, and leadership in taking decisions about what treatment will be of benefit to the patient, and when treatment goals should shift to best supportive care and planning for dying well.<sup>34</sup>

#### **Implications for future research and clinical practice**

Planning for future care has the potential to promote

patient autonomy and can offer a valuable means to increase public and professional dialogue about end-of-life care. Given its complexity, it is important to understand more about how best to respect individual patient and family preferences for information about their illness and prognosis, and how to support them if they wish to make choices in different illnesses, circumstances, and settings. Thus, interviews with patients as well as professionals are indicated.

It is important to acknowledge the extensive professional experience, values, and current approaches towards good care of the dying in primary care. Fostering hope through discussing reasonable options for future care and treatment and ways of managing uncertainty, alongside personal and family goals, should be at the centre of any care-planning process. The patient-held advance care plan developed in this study needs to be evaluated further in primary and secondary care and with patients who have palliative care needs from any advanced illness. It may offer a means of encouraging patient autonomy while retaining best practice in the art of personalised primary care, as advocated in the recent General Medical Council guidelines.<sup>35</sup> However, even more basic research may first be needed to find out how best to identify patients in primary care routinely who could benefit from a palliative care approach, as the majority of such patients are not currently being identified.

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The authors have stated that there are none.

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## Appendix 1. Future care plan.

### Making plans for my future care

Helping you to take control and make your choices heard.

This Plan belongs to:

#### Some information for you

To be able to give the best care to people with a serious illness, we need to talk about what is important to each person and their family now and in the future. This 'Future Care Plan' can help you to think about what things are important so you can talk about them with your family and the people who are looking after you.

#### What is a Future Care Plan?

It is a Plan that some people like to use to write down important information about their plans and wishes for the future. It helps other people know what your wishes are.

#### What goes in the Plan?

You can use the Plan in any way you like. You can put in information about the kind of care and treatment you want to have, and where you would like to be cared for in the future as well as the things about your life that are important to you.

#### What doesn't need to go in the Plan?

The Plan is not a medical or legal document so you don't need to put medical or legal information in it unless you want to.

#### Do I have to have one?

No. It is up to you. Some people just use the Plan to help them talk about things with their family or professionals like their doctor or nurse.

#### When should I start one?

Many people like to start thinking about issues to do with their care a long time in advance while they are feeling well. Other people like to wait until later.

#### Any more questions?

We have put some more ideas about ways you might fill in this Plan at the end.

### My Plans and Thoughts

#### Planning ahead

(eg. Important events coming up, things I want to do in the future, things that I enjoy now and want to carry on doing.)

#### Looking after me well

(Things about my treatment and care which are important to me.)

#### My concerns

(Things that worry me now and any worries about what might happen in the future.)

#### Other important things



## Appendix 1 continued. Future care plan.

**Things I want to know more about**

Some people like to know about other things that can be important to someone with a serious illness and their family. Some of these are:

- Asking a person you can trust to speak for you and help make decisions about your health if in the future you are not able to do it yourself (a Welfare Attorney).
- A living will or advance decision to refuse a specific treatment
- Benefits advice
- Cardiopulmonary resuscitation decisions (DNA CPR): attempting to restart a person's heart

Things I want to ask about are:

**Keeping track**

(Each time you write in this Plan, you might like to write down the date and the name of anyone who helped you in this box.)

If you have added any extra pages please write down how many there are here:

**Suggestions for filling in your Plan****How do I fill it in?**

We have put boxes in to give you a few ideas about what some people want to write about. Some people fill in all the boxes. Other people just write in one or two. Sometimes people want to add a different page or box of their own. You can fill in your Plan all at once or bit by bit, and you can change it whenever you want.

**Who can help me fill it in?**

Anyone can help you fill this Plan in. Some people like to do it themselves, others like to fill it in with help from friends, family or professionals like your doctor or nurse. If someone does help you, please write down their name at the end.

**Filling in the boxes**

If you want to use the boxes then here are some suggestions for you.

**Planning ahead:** Write about the things that are important to you. Think about what you enjoy doing or want to do in future. Make a note of any important family events coming up. That way everyone can plan ahead and offer help if you need it.

**Looking after me well:** Write down any thoughts you have about where you might be cared for in the future and what kind of treatment and care you might want to have. This information can help the professionals looking after you try to make sure it happens.

**My concerns:** You can write about any worries you may have about yourself or your family, pets and so on. This way you can talk about them with someone you trust.

**Other things:** You can write anything in here that you think is important but does not fit anywhere else.

**Things I want to know about:** You can use this box to keep track of any questions you want to ask and the answers you got.

**Where should I keep my plan?**

You should keep your Plan with you. If you wish, your doctor can keep a copy at the practice.

**Useful contacts:**

My GP's name and telephone:

My district nurse's name and telephone:

Other important people:

# Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study

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## ABSTRACT

**Objective** To refine and evaluate a practical, clinical tool to help multidisciplinary teams in the UK and internationally, to identify patients at risk of deteriorating and dying in all care settings.

**Methods** We used a participatory research approach to refine the 2010 Supportive and Palliative Care Indicators Tool (SPICT) and evaluate its use in clinical practice. We conducted an ongoing peer review process for 18 months via an open access webpage, and engaged over 30 clinicians from the UK and internationally in developing an effective tool. Secondly, we carried out a prospective case-finding study in an acute hospital in SE Scotland. Four multidisciplinary teams identified 130 patients with advanced kidney, liver, cardiac or lung disease following an unplanned hospital admission.

**Results** The SPICT was refined and updated to consist of readily identifiable, general indicators relevant to patients with any advanced illness, and disease-specific indicators for common advanced conditions. Hospital clinicians used the SPICT to identify patients at risk of deteriorating and dying. Patients who died had significantly more unplanned admissions, persistent symptoms and increased care needs. By 12 months, 62 (48%) of the identified patients had died. 69% of them died in hospital, having spent 22% of their last 6 months there.

**Conclusions** The SPICT can support clinical judgment by multidisciplinary teams when identifying patients at risk of deteriorating and dying. It helped identify patients with multiple unmet needs who would benefit from earlier, holistic needs assessment, a review of care goals, and anticipatory care planning.

## INTRODUCTION

Timely identification of people who are at risk of deteriorating and dying is a

prerequisite for effective end-of-life care and a key element of health policies in the UK and internationally.<sup>1–7</sup> Identification prompts clinicians to initiate proactive holistic needs assessment, shared decision making about goals of care and anticipatory care planning. However, patients are often identified too late in their illness. General practitioners and hospital specialists both report difficulties with earlier recognition.<sup>8–10</sup> Effective triggers for patient identification are underdeveloped in contrast with other more established tools for end-of-life care planning and service delivery.<sup>1–5</sup> The emphasis has been on predicting prognosis more accurately in order to introduce palliative care at an appropriate time. The widely used ‘Surprise question’ (*Would you be surprised if this patient died within the next 12 months?*) is combined with clinical indicators of advanced conditions in referral criteria for hospice and palliative care in the USA and in the UK Gold Standards Framework Prognostic Indicator Guidance.<sup>4–11</sup> If used alone, the surprise question may identify too many patients for palliative care; a third of all inpatients in a recent UK hospital prevalence study.<sup>12</sup> Mortality risk assessment models for single diagnoses are often used by hospital specialists but are of limited value because multimorbidity is now the norm in those with advanced, long-term conditions.<sup>13–14</sup> Even in patients with cancer, scores based on biomarkers gave similar prognostic estimates to a multidisciplinary team assessment and were less accurate with longer survival times.<sup>15</sup>

Linking identification of patients for supportive and palliative care with estimates of prognosis means that clinicians

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## Research

tend to focus on when to start 'planning for dying' and may delay a review of care goals and unmet needs until the last weeks of life.<sup>16</sup> Earlier identification requires a change from estimating when a patient may die to identifying those who are at sufficient risk of deteriorating and dying for proactive assessment and care planning to be appropriate. This includes people with advanced, progressive, incurable conditions, general frailty and coexisting conditions, and those at risk of dying from a sudden acute crisis in their condition or from life-threatening acute conditions caused by sudden catastrophic events.<sup>3 17</sup>

The Supportive and Palliative Care Indicators Tool (SPICt 2010) was designed to provide practical, evidence-informed guidance to help clinicians working in primary and secondary care recognise when their patients might be at risk of dying and likely to benefit from supportive and palliative care in parallel with appropriate ongoing management of their advanced conditions.<sup>18</sup> The SPICt supports multidisciplinary assessments of individual patients based on clinical observations, performance status, symptoms, multimorbidity, illness trajectories and the patient's views and goals.<sup>5</sup> This paper reports the development and evaluation of the tool.

## METHODS

Since April 2011, we have developed and evaluated the SPICt using a mixed-methods, participatory approach.<sup>19</sup> The research team included palliative care specialists, primary care clinicians, hospital clinicians, and a senior social scientist as the project researcher. Peer review and consensus building contribute to the development of tools with good face validity and utility in routine clinical practice, so we offered open access, via a designated webpage, to each of the 15 major revisions of the SPICt that were developed over an 18-month period. This is now the SPICt project website (<http://www.spict.org.uk>). An international, electronic mailing list was built from a wide spectrum of interested clinicians and policy makers who contacted us from the UK, Europe, USA, Canada, New Zealand, Australia and Africa. We also invited primary and secondary care leads for palliative care in Scotland, England and Ireland to participate. After each amendment had been agreed by the project steering group and integrated into the next version of SPICt, email alerts were sent to all our peer reviewers seeking comments and suggestions until no further changes were proposed.

At the same time, we carried out a prospective, case-finding study of patients with advanced kidney, liver, cardiac, or lung disease following an unplanned admission to a tertiary, acute hospital in SE Scotland. The research team worked alongside clinical staff in each of the four participating units in turn, supporting data collection, analysis and interpretation.<sup>20</sup> Senior nursing staff and specialty registrars agreed to screen

all their patients soon after an unplanned admission using a checklist of SPICt clinical indicators for an 8 week period. The checklist contained the SPICt general indicators, the surprise question and disease-specific indicators relevant to the patients in each unit (see online supplementary appendix 1: Liver unit checklist). The staff recorded demographic and clinical details, admission outcome and service use data (unplanned admissions and hospital bed days) for all patients with the SPICt indicators of advanced conditions. The patients were then followed for 12 months by the research team using the hospital electronic patient record system. These data were analysed using a customised Excel database.  $\chi^2$  Tests for categorical variables were used to compare the SPICt indicators in patients who died and those still alive at 12 months. Scottish Patients at Risk of Readmission and Admission (SPARRA) scores were calculated by the Scottish Information Services Division.<sup>21</sup> SPARRA scores are a proxy measure of deteriorating health because patients in the last year of life have increasingly frequent unplanned hospital admissions.<sup>22</sup> We calculated the Charlson renal comorbidity index for patients with kidney disease and the UK end-stage liver disease (UKELD) score for liver unit patients.<sup>23 24</sup>

## RESULTS

## SPICt redesign

Six parameters underpinned the conceptual design of the SPICt, and our peer reviewers agreed they should be retained (box 1).

The 2010 SPICt indicators were reviewed and compared with similar tools identified from the literature to achieve consensus about the items for each section and their wording.<sup>6 7 11 25</sup> General indicators of deteriorating health identified in several other

## Box 1 Supportive and Palliative Care Indicators Tool (SPICt): key elements

- ▶ Simple, one-page format.
- ▶ Readily identifiable general indicators of deteriorating health commonly present in advanced conditions.
- ▶ Evidence-based clinical indicators of all the major advanced, life-limiting conditions and multimorbidity.
- ▶ Good face validity for health and social care professionals working in hospital, community and care home settings in the UK and internationally.
- ▶ Promotes early supportive and palliative care in parallel with optimal management of any underlying conditions as part of routine clinical practice.
- ▶ Contains accessible language and concepts that can be used to initiate discussions with patients and families about goals of care and improve communication between professionals/teams.



palliative care assessment tools, or found in disease-specific mortality tools, are in the first section of the SPICT. We chose the Malnutrition Universal Screening Tool for the weight loss indicator as it is recommended for use throughout National Health Service (NHS) Scotland.<sup>26</sup> Descriptions of symptoms were used instead of disease severity scores, for example, in advanced lung and heart disease, to make the tool more accessible (see online supplementary appendix 2: SPICT 2013). Many of the hospital clinicians in our case study and peer review group, and some primary care professionals, said the surprise question was of limited value if they did not know the patient well, or if the patient was at risk of dying but currently more stable. Our collaborative approach has led to continuing partnerships with projects using the SPICT to identify patients in primary and secondary care settings.<sup>7 27</sup>

#### Implementation and evaluation of SPICT

Ward staff completed checklists containing demographic details and SPICT clinical indicators for 130 patients with advanced organ failure following an emergency hospital admission (table 1). The renal team identified 41% of their unplanned admissions (55, n=133) and the liver unit 83% (35, n=42). The cardiology unit screened 570 admissions but only identified 2.8% (16 patients) due to a change in the types of patients being admitted to the ward after the study was planned. Workload pressures meant the respiratory unit struggled to screen all admissions, but the participating ward staff identified 24 patients using the SPICT checklist by asking senior ward staff or the respiratory specialist nurses to direct to them newly admitted patients with advanced lung disease. The major diagnoses were vascular disease, alcoholic liver disease, ischaemic heart disease, and chronic obstructive pulmonary disease. Multimorbidity, defined as two or more active long-term conditions,

was common (77%). Patients were usually admitted with acute medical problems relating to their underlying advanced conditions. Almost all the patients were discharged home but 35% (45) died within 6 months. By 12 months, 48% (62) had died; 69% (43) of these patients in hospital (table 2). Most patients had a short final admission (median 10 days, range 1–60 days) and half the deaths were within 88 days of patients first being identified. Five patients had a sudden terminal event. However, the majority followed an archetypal organ failure trajectory and died of multiple complications of their advanced conditions, usually after an acute deterioration on a background of progressive decline.

The SPICT indicators identified in patients who died and those still alive at 12 months are shown in figure 1. A significantly greater number of patients who died, compared with those who survived for over 12 months, had: two or more unplanned admissions in the 6 months before they were screened (69% vs 37%,  $p<0.001$ , 95% CI on the difference=33±16), persistent symptoms despite optimal treatment of their underlying conditions (60% vs 24%,  $p<0.001$ , 95% CI 36±16), and increased care needs (40% vs 13%,  $p<0.001$ ; 95% CI 27±15). There was some variation between patient groups. A poor or deteriorating WHO performance status affected 60% in total, but only a quarter of the liver unit cases. Weight loss occurred in a third of renal unit patients but in less than 5% of the other groups. The SPICT performed as well as the standard mortality tools. The renal unit patients who died had a mean Charlson renal morbidity index of 7.9; a score of 6+ predicts a 1-year survival probability of about 0.6. In the liver unit, SPICT identified patients had a mean UKELD score of 57; a score of 60 predicts a 50% 1-year survival in advanced liver disease. The ward teams identified many of the patients who had died by 12 months (79%) with the surprise question. They thought that

**Table 1** Demography of Supportive and Palliative Care Indicators Tool (SPICT)-identified patients (130)

Unit	Mean age (range)	Main diagnosis	Main admission reason
Renal (55)	65 (34–88)	Vascular disease	23
		Primary renal disease	15
		Myeloma	4
		Other	13
			Fluid overload
Liver (35)	57 (32–88)	Alcoholic liver disease (ALD)	26
		Non-alcoholic fatty liver disease	4
		Secondary liver cancer+ALD	1
		Other	4
			Pain/symptom control
Cardiac (16)	76 (55–89)	Ischaemic heart disease	11
		Cardiomyopathy	3
		Other	2
			Myocardial infarction
Respiratory (24)	74 (49–87)	Chronic obstructive pulmonary disease (COPD)	17
		Pulmonary fibrosis	2
		Lung cancer+COPD	1
		Other	4
			Exacerbation of COPD
			Pneumonia+multimorbidity
			Haemoptysis
			Pleural effusion

## Research

**Table 2** Outcomes for Supportive and Palliative Care Indicators Tool (SPICT)-identified patients

Unit	First admission		Deaths at 6 months All deaths	Deaths by 12 months		
	Died	Discharged		Hospital	Community	All deaths (%)
Renal (55)	3	52	19	15	5	20 (36)
Liver (35)	–	35	13	13	6	19 (54)
Cardiac (16)	4	12	8	7	4	11 (69)
Respiratory (24)	2	22	5	8	4	12 (50)
Total (130)	9 (7%)	121 (93%)	45 (35%)	43 (69%)	19 (31%)	62 (48)

71% of the group as a whole was at risk of dying within 12 months. Despite this perception that many of the identified patients might die, relatively few had a 'Not for cardiopulmonary resuscitation' form in place at the time of their initial SPICT screening; 24% overall and 39% of those who died.

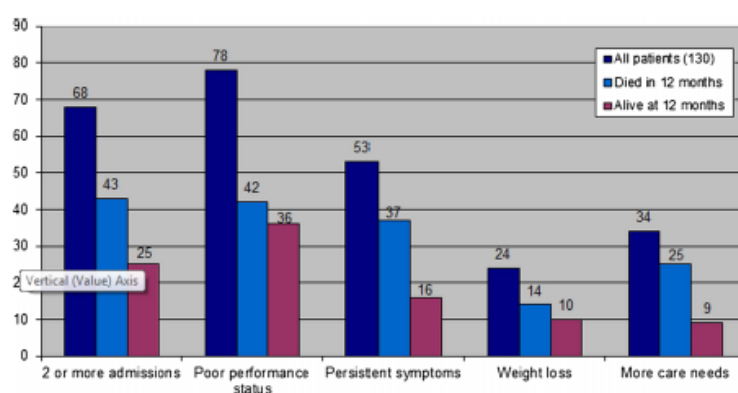
In addition to documenting how many of the patients had two or more admissions when screened with the SPICT, we recorded admissions and bed days during the last 6 months of life for the 62 patients who died. These patients had a mean of 2.4 unplanned admissions (range 1–7), a median number of hospital bed days of 34.5 (range 3–130 days), and spent 22% of their last 6 months of life in hospital. We also recorded these service use outcomes for the 68 patients who survived during the first 6 months after they were identified. They had a mean of 2.2 admissions (range 1–7), a median number of hospital bed days of 21.5 (range 3–167 days) and spent 17% of that 6 months in hospital. This high use of hospital services by all the patients identified was reflected in the SPARRA scores at discharge following the initial admission. These showed a 65% median readmission risk for those who died and a 60% risk in those who were still alive.

## DISCUSSION

The SPICT is a simple tool consisting of easily recognised, clinical indicators of advanced illness. It can support the clinical judgment of multidisciplinary

teams in primary and secondary care as they seek to identify patients who might benefit from supportive and palliative care assessment and care planning. The SPICT has been further developed and evaluated in this study using a mixed-methods approach that combined peer review with a detailed case study and web-based dissemination. The tool is now being used in clinical practice by SPICT partner projects caring for patients with a wide range of advanced illnesses in hospitals, the community and care homes in the UK and internationally.<sup>7 26</sup> In our hospital-based, case study of patients with advanced non-malignant illnesses, those who died had a higher frequency of SPICT general indicators than those who survived for 12 months, particularly unplanned hospital admissions, persistent symptoms and increasing care needs.

More emphasis on identifying patients with advanced conditions who are at risk of deteriorating and dying will encourage clinicians to consider a review of care goals and interventions to improve quality of life earlier in the illness trajectory. Simple identification tools based on accepted clinical indicators, such as SPICT, are needed to support this change in practice. Better identification, holistic assessment and anticipatory care planning for future deterioration, could help to reduce the substantial risk of unplanned hospital admissions and prolonged inpatient stays experienced by all the patients we identified.<sup>21 27 28</sup> Primary care teams have previously indicated that they would welcome guidance from hospital specialists

**Figure 1** Indicators of deteriorating health in Supportive and Palliative Care Indicators Tool (SPICT)-identified patients.



about when to put patients on their palliative care registers or open discussions about future care goals.<sup>5 25</sup> The SPICT indicators offer guidance on which patients are at risk of deteriorating, and describe changes in health status and care needs that can be used as a starting point for these discussions. The SPICT has been developed and refined in partnership with clinicians working in hospitals, general practice and other community settings with the specific aim of producing a common set of clinical indicators that can support effective communication, shared care and a range of palliative care service developments for patients who transition frequently between care settings.<sup>27</sup> Additionally, it identifies patients with advanced liver disease, a rapidly rising cause of mortality among people under 70 years in the UK,<sup>30</sup> as well as the many patients with multiple advanced conditions including frailty and dementia. Future work could address the value of combining the SPICT with established needs assessment tools designed to help clinicians who provide generalist palliative care to identify patients who have more complex needs.<sup>31 32</sup> Some of these patients and families will benefit from referral for specialist palliative care, as indicated in the SPICT section on assessment and planning.<sup>33</sup>

Although the hospital ward staff told the research team that they were aware of a group of patients with advanced illness who were often readmitted with an acute or chronic deterioration, and who might well die in the next year, a substantial number of the SPICT-identified patients were still for cardiopulmonary resuscitation despite having a very low chance of a medically successful outcome. Identification is only the first step in addressing the multiple, complex barriers that hinder successful introduction of earlier palliative care in acute hospital settings.<sup>12 16</sup> Primary care clinicians have said they prefer an individualised, needs-driven approach to introducing palliative care, and often use triggers such as poorly controlled pain or a requirement for increased support from the multidisciplinary team.<sup>29 34</sup> Combining population and service-based screening with individual patient assessments by clinicians, undertaken as part of routine care, could be the most effective way to integrate public health and patient-focused approaches to earlier identification.

#### Strengths and limitations

The SPICT has been developed from the available evidence base and subject to thorough peer review by a wide range of clinicians who see the need for a pragmatic tool to improve clinical practice. We conducted a case study in one urban area in SE Scotland with relatively small numbers of patients and few from black or minority ethnic groups. We faced the challenge of clinical research in busy care settings, and this limited our ability to survey all admissions in some wards. We did not collect data on outcomes for the

patients who were screened but not identified as this was not feasible. Future studies could evaluate the sensitivity and specificity of the SPICT in larger populations. However, it is the identification of individual patients at sufficient risk of deteriorating and dying to prompt a review of their care that is important. The effectiveness of the SPICT in clinical practice needs to be evaluated more extensively in different settings and with a wider range of patients. Although our peer reviewers came from diverse professions, settings and countries, they were a self-selected sample of interested professionals and policy makers. Ongoing peer review and comment via the website should ensure further refinements are made to the tool over time by a wider group of participants.

#### CONCLUSIONS

Key components of effective palliative and end-of-life care are patient identification, assessment and care planning. Unless screening patients with advanced conditions becomes routine practice in all care settings, many patients will not benefit from the improvements being made to the care of people who are at risk of deteriorating and dying. A simple tool to support better identification of patients with unmet general palliative care needs is essential, and the SPICT addresses this gap. Shifting the emphasis to a focus on quality of life as the main goal of care is challenging. The SPICT provides clear indicators which clinicians can use to initiate conversations with patients and families about their preferences for different treatment and care options. Additionally, adopting a common, shared tool promotes effective communication and coordination between primary and secondary care teams.

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**Contributors** KB and SM designed the study and KB was the principal investigator; GH was responsible for the data collection supported by KB and DC; KB designed the SPICT project website; KB, GH, DC and SM were involved in data analysis and interpretation. The final manuscript was written by KB with contributions from the other authors. All the authors read and approved the submitted version.

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**Competing interests** None.

**Ethics approval** The study was approved by the NHS Lothian research ethics committee and the NHS Lothian Caldicott Guardian.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** The project Excel database has been retained by the principal investigator and contains no patient identifiable data. Further information can be obtained from the corresponding author.

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# 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers

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## ABSTRACT

**Objective** Multimorbidity is increasingly common in the last year of life, and associated with frequent hospital admissions. The epidemiology is well described, but patient perspectives are less understood. We report the experiences and perceptions of people with advanced multimorbidity to inform improvements in palliative and end-of-life care.

**Design** Multicentre study including serial, multiperspective interviews with patients and their family carers; an interpretive analysis of experiences and understanding of living with advanced multimorbidity.

**Participants** We recruited patients and their family carers using established UK clinical guidance for the identification of people anticipated to be in their last year of life.

**Settings** An acute admissions unit in a Scottish regional hospital; a large English general practice; a London respiratory outpatient clinic.

**Results** We analysed 87 interviews with 37 patients and 17 carers. They struggled with multiple changing medications, multiple services better aligned with single conditions such as cancer, and a lack of coordination and continuity of care. Family carers spoke of physical, mental and emotional exhaustion and feeling undervalued by professionals. Patients and carers frequently saw deteriorating health as part of 'growing old'. Many used a 'day-to-day' approach to self-management that hindered engagement with advance care planning and open discussions about future care. 'Palliative

care' and 'dying soon' were closely related concepts for many patients, carers and professionals, so rarely discussed.

**Conclusions** Patients with advanced multimorbidity received less care than their illness burden would appear to merit. Some people did restrict their interactions with care providers to preserve autonomy, but many had a limited understanding of their multiple conditions, medications and available services, and found accessing support impersonal and challenging. Greater awareness of the needs associated with advanced multimorbidity and the coping strategies adopted by these patients and carers is necessary, together with more straightforward access to appropriate care.

## INTRODUCTION

Delivering better care for the increasing numbers of people with two or more chronic illnesses poses substantial challenges for health and social care systems which have previously focused on single diagnoses with multimorbidity largely ignored.<sup>1–4</sup> The need to develop more effective, person-centred care for people living with multiple long-term conditions has been recognised but interventions have shown mixed results.<sup>5–6</sup> As multimorbidity becomes the norm in the last year of life, patient and carer experiences must inform improvements in palliative and end-of-life care.<sup>7–8</sup> These patients spend most of their last year of life at

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home being cared for by family, general practitioners, community nurses and voluntary sector services; many receive outpatient care.<sup>9 10</sup> Hospitals remain the most common place of death.<sup>10</sup> Caring for someone with multimorbidity at home places a considerable burden on family carers.<sup>11</sup> While patients with a single, dominant illness often have a keyworker or named specialist, family carers of people with several conditions frequently face the additional challenge of coordinating care from multiple services.<sup>12 13</sup>

While conducting a multicentre study on experiences of coordination of care for people considered by professionals to be in their last year of life, we found significant differences in the care experiences of people with two or more advanced illnesses compared with those who had one readily identifiable diagnosis.<sup>12 14</sup> We carried out a more detailed analysis of the interviews with this large subgroup (37 of 56 patients and their carers). We classified this group as having 'advanced multimorbidity' which we defined as multiple, life-limiting illnesses or progressively deteriorating health due to several long-term conditions.

## METHODS

Serial, multiperspective interviews were conducted with patients and their family carers recruited in one of three settings: a large, general practice serving multiethnic urban and rural locations in England, an acute admissions unit in a Scottish teaching hospital, and a respiratory outpatients department in a central London teaching hospital.<sup>14</sup> Interviews with patients with advanced multimorbidity and their family carers were selected for additional analysis.

## Recruitment

Staff in the three settings identified patients they considered to be in the last year of life using the question 'Would you be surprised if this patient died within the next 12 months?'<sup>15</sup> A purposive sampling strategy enabled us to recruit a diverse sample of adults according to their diagnoses, age and social criteria. Patients were asked to nominate a family carer who consented separately to participate. Patients with moderate to severe cognitive impairment and those under 18 years were excluded.

## Data collection

Experienced, qualitative researchers (BM, VN and EE) conducted semistructured, serial interviews with patients and case-linked family carers at 8–12 weekly intervals, using a multiperspective approach.<sup>16 17</sup> Patients were interviewed in their own homes, usually with their family carer if they had one. Participants were invited to talk about their understanding of their health conditions and their experiences of receiving care from different care providers and settings. Each patient was followed for 5–9 months.

## Analysis

The interviews were audio-recorded, transcribed and imported into NVivo software for analysis.<sup>18</sup> Data from each setting was analysed separately. A constructivist approach was taken and thematic analysis chosen because of its utility in comparing data from divergent sources.<sup>19</sup> Cross-case analysis was then conducted to produce an integrated understanding of themes across settings and in different contexts. Interpretive analysis of the subgroup with multimorbidity explored themes pertaining to experiences and understanding of living with deteriorating health due to multiple conditions.

## RESULTS

Thirty-seven (66%) of the 56 patients in the larger study had advanced multimorbidity as defined above. Eighty-seven semistructured interviews were conducted with this subgroup: 42 with patients alone, two with carers alone and 43 as joint interviews. Participants completed one (8), two (10) or three (19) interviews. Within 9 months, 11 (30%) had died. The patients had an average age of 76 years (range 55–92 years), and 23 of the 37 were male. They had multiple conditions including heart, respiratory, liver and renal failure, lung cancer, neurological conditions and mild dementia.

Lacking a diagnostic framework to help them make sense of their multiple illnesses, participants drew on lay *understanding* of their conditions which was reinforced by their *experiences* of care. To exemplify this, we have divided the findings into two themes: experiences and understanding.

### Experiences of care: multiple services

As might be expected, the patient and carer experiences reflected a continuing struggle to cope with multiple care systems, services and staff. At the same time, they tried to maintain a semblance of normality amidst growing feelings of dependency. Participants gave accounts of complicated, confusing and sometimes unresponsive services. Lack of care coordination and continuity among the numerous service providers led to perceptions of inconsistent and impersonal care. No diagnostic label and little explanatory language to describe their health problems made requesting appointments or a general practitioner (GP) visit difficult. Attending clinics was physically demanding and these often failed to address complex, ongoing problems. Many patients took more than 10 different medicines daily. Frequent medication changes, usually associated with hospital admissions, led to doubts about their purpose and efficacy. Carers had to deal with the increasing physical and emotional demands of caring, oversee multiple medications, and do all this with little indication of how long it might last. Patients without a family carer struggled to manage everything by themselves.

Carer: 'There is no consistency in terms of seeing the same doctor all the time. So many changes, so many different doctors.... Each of them is very considerate but clearly clueless about the uniqueness of the patients. And the whole business of having to re-educate and re-inform each time you go in. (Carer for P7—female, 89: syncope, heart disease)

Patient: 'You can phone in and the doctor will talk to you or you can phone a nurse and they will talk to you. 'Please don't make an appointment unless it is absolutely necessary.' Well, what do you know is absolutely necessary? I have been rushed into hospital because I have left it too long, because I won't bother them.' (P8, female, 75: diabetes, hypertension)

Carer: 'It really pays you to keep your own record of these things because, you had been on and off and back on and downgraded and upgraded so many times, it's almost impossible now, to think back and say, what was that for again?' (Carer for P17—female, 79: heart failure, diabetes)

Carer: 'I said I was going to need some carers to come in at bed time and things because I wouldn't manage on my own, and I was getting things like 'well you've managed all these years Mrs S' and I said well he had two legs and he's got one leg now. And I said I'm not as young as I was.' (Carer for P26—male, 67: chronic obstructive pulmonary disease (COPD); peripheral vascular disease, renal failure)

#### Understanding of deteriorating health due to multiple conditions

Patients and carers drew on their experiences of the healthcare system, their beliefs about illness and accounts from friends, family and the media to try to make sense of their health problems and treatments. The most common interpretation was that the various conditions suffered by the patient were inevitable effects of aging.

Patient: Believe you me what between my kidneys and my heart and my lungs they're all working overtime and they're all beginning to show wear and tear which is only right at my age. (P1, male, 82: COPD, heart failure, renal failure)

Patient: I've still got me brain, you see. My body's falling apart but my brain is still alright. I've had a piece taken off me colon. I've got this chest trouble, and I've got all sorts of bits like angina and high blood pressure and, all these little things. That's what I mean by falling apart (laughs). I need MOTs [ministry of transports] every now and again, you know? (P33, female, 90: lung cancer, angina, COPD, osteoporosis)

This understanding of deteriorating health as '*old but not ill*' was used to rationalise perceived failings of the healthcare system. Some suggested that their care was poorer because they were 'older,' leading to complaints about inequity. Beliefs about just being old meant that these people generally focused on living as

well as possible in the present. They avoided planning ahead and only sought help if they were very ill or unable to cope. Not depending on services was seen as a way to preserve autonomy, and being a carer was a responsibility to be accepted not questioned.

Carer: 'We deal with everything just as it is happening, just day-to-day stuff and things. We go out to appointments. But you are not really fussy about going out much and things. We just manage.' (Carer for P11—male, 87: renal failure, mild dementia)

Carer: 'I personally don't want anybody to come in because we cope ourselves and the way we cope is because we cooperate with one another you know. The way I look at it is it's for better or worse isn't it?' (Carer for P2—female, 76: heart failure, renal failure, diabetes)

Patient: 'If I'm not ill I don't go to the doctor's, I don't go to a hospital; you know what I mean?' (P35, male, 69: lung cancer, COPD, emphysema)

There was little evidence of integrated care planning or any open discussions about the future between patients, family carers and health professionals. Talking about planning ahead or deteriorating was viewed negatively by some people who had no experiences of doing so. Patients and carers were often unaware of the patient's risk of dying. When a crisis or death did occur, it often felt unexpected, even if the GP had hinted that it could happen at any time. None of the participants showed any understanding of the potential benefits of planning ahead to optimise quality of life and death. Deteriorating health due to multiple illnesses was interpreted as 'getting old' so palliative care, which was largely associated with managing imminent death, had no role to play.

Patient: Nope, nope nobody has ever ... said anything to me about that and I've never broached the subject 'cause I think I'd rather be positive. I think I'm not going to get worse. (P5, female, 66: liver failure, diabetes, heart disease)

Carer: [Her death] was totally unexpected. [The GP] did say to me, just after Christmas when he had been up.... And going outside, he says, she is on a knife edge, I hope you are prepared. It could happen anytime. I'd say, for the past year and a half.' (Carer for P2—female, 76: heart failure, renal failure, diabetes)

## DISCUSSION

### Summary of findings

Patient experiences of multimorbidity towards the end of life were mostly of progressive physical decline with increasingly frequent episodes of acute deterioration, multiple changing medications, progressive loss of autonomy, poor or inconsistent communication, and inadequate continuity of care from numerous but disconnected services. Consequently, the physical and



emotional burden of managing care usually fell on the patient or a family carer. Lacking a coherent framework to articulate their experiences and problems, patients and carers tended to interpret their deteriorating health and its consequences as a case of 'getting old' rather than being progressively more unwell. As a result, they sometimes failed to seek the right help and support, or did not receive it, from care systems not configured to respond to their needs. For these people dying from multiple advanced conditions, the daily burdens were great and crises were common yet there was little evidence of proactive and coordinated services delivered as part of a person-centred palliative care approach.

#### Strengths and weaknesses

The involvement of three research teams, a shared protocol, purposive sampling of participants with diverse diagnoses receiving a broad range of services, and structured data integration and analysis enabled us to highlight diversity and commonality in the different settings. Serial interviews helped establish close relationships with participants and showed how services were experienced over time. Use of the 'surprise question' meant we recruited patients with multiple advanced conditions whom clinicians considered to have a considerable disease burden and a substantial risk of dying within the next year. However, this meant that our participants were identified largely on the basis of physical health problems likely to have a poor prognosis. Concurrent mental health problems were probably under-recognised. Patients with moderate to severe cognitive impairment had to be excluded because of difficulties with consent and participation in an interview study. This group of patients approaching the end of life and their carers had experiences of poor care coordination and polypharmacy that were similar to the wider population of patients who have multiple chronic illnesses. In addition, such patients have a high risk of further deterioration, unplanned hospital admissions and poor end-of-life care.<sup>8</sup>

#### Comparison with existing literature

Our results confirm the difficulties patients and carers face in conceptualising chronic illnesses. Patients can regard chronic obstructive pulmonary disease as a 'way of life' rather than an illness.<sup>20</sup> Patients with heart failure rarely understand the condition or treatment aims.<sup>21</sup> Participants in this study regarded their health problems due to advanced multimorbidity as a normal part of ageing, albeit sometimes prematurely. Patients and carers thought crises occurred when one particular problem became acute, and were resolved when that problem was treated. In this respect, the experiences of people with advanced multimorbidity are analogous to the fluctuating health associated with

advanced organ failure. Uncertainty impacts on all aspects of the well-being of patients and carers.<sup>22-23</sup>

Just as people with non-malignant conditions such as heart failure or chronic obstructive pulmonary disease get less support for an equivalent symptom burden compared with those who have lung cancer, people with advanced multimorbidity appeared to seek and obtain less support and care coordination than their total burden of illnesses would merit.<sup>21-24</sup> Their experiences and understanding of their illnesses and available services were generally poorer than patients with a single illness.<sup>12</sup>

Despite calls for earlier palliative care, in practice it often starts in the last few weeks of life or the patient does not receive palliative care at all.<sup>25</sup> Although many participants would have benefited from a palliative care approach (providing holistic and anticipatory care), it was generally only those with a secondary cancer diagnosis who were in receipt of any generalist palliative care. Patients and carers without a cancer diagnosis did not discuss the possibility of palliative care unless they were prompted. In a recent study, around 80% of people with one or more advanced non-malignant illnesses died before they were identified as having the potential to benefit from generalist or specialist palliative care.<sup>26</sup>

The actions of patients and carers can be understood as a form of lay epidemiology.<sup>27</sup> Without a clear understanding of multimorbidity, patients and carers develop 'empirical beliefs in a partial and piecemeal manner' from direct and indirect experiences and through drawing on 'metaphors' to explain their condition.<sup>27-29</sup> In this study, the metaphor most frequently used to explain their health to others was one of the body 'failing like an ageing car'. In a review of metaphors in palliative care, Southall described several potentially empowering examples, such as considering oneself to be 'at war' with a disease, which are commonly adopted in cancer.<sup>29</sup> In the context of deteriorating health due to multiple advanced conditions, a metaphor that focuses on the inevitability of breakdown due to ageing risks disempowering patients and family carers and may lead to a fatalistic acceptance of their situation.

Our results also reflect Townsend's analysis of living with multimorbidity being that of an attempt to maintain a sense of normality wherever possible.<sup>30</sup> One approach our participants used was to minimise their use of services and to seek support from relatives and informal networks of friends and neighbours instead. Another was to maintain as many routine activities as they could manage for as long as possible. Chochinov portrays these types of activities as 'dignity conserving' in that they seek to preserve a sense of self-worth, identity and autonomy.<sup>31-32</sup> Our participants' actions can therefore be seen as rational responses to their experiences. Many in the study used a 'day-to-day' approach to self-management that limited engagement

with advance care planning and open discussions about future care. Some patients also found it a negative experience to talk about the future in this way. An European Union study has shown that a large proportion of the public prefer to not make decisions about their care in advance of incapacity and that financial hardship, educational attainment, age, and preferences regarding quality and quantity of life require further examination in relation to shared decision-making.<sup>33</sup> This study helps explain some of the understanding and behaviours that influence engagement in advance care planning.

## CONCLUSIONS AND POLICY IMPLICATIONS

This study reveals important aspects of the experiences of end-of-life care in patients with advanced multimorbidity and their family carers that should influence future service developments. We agree with Mercer that an understanding of multimorbidity as the coexistence of two or more morbidities is too simplistic.<sup>34</sup> It risks reducing a patient to the sum of their illnesses and so potentially underestimates the totality and complexity of their needs and experiences. We suggest that what is required is the holistic management of such patients by generalist clinicians in the community providing continuity of care and overall care coordination, and accessing specialist care where necessary.<sup>4 6 35 36</sup> Interventions which can enable professionals and services to deal with more than just the acute problem will be required to provide individualised care based on a holistic understanding of patient and carer needs.<sup>37</sup> This may require additional resources or changes in primary care systems to support better recognition and planned care of people dying unpredictably with multiple illnesses. Reducing the negative impact of unplanned hospital admissions is important, for example through good coordination with out-of-hours providers. The burden of multiple, changing medications could be mitigated in part through routinely providing information and support when changes are proposed and by arranging periodic reviews of medication in collaboration with patients and family carers. Facilitating their own strategies for living as well as possible with advanced illnesses requires greater dialogue about the benefits of accepting more help and how best to provide it.

We need a change of culture to encourage proactive care while at the same time helping to maintain a sense of identity as a 'normal' old person. Systematic approaches that will help professionals identify their patients with advanced multimorbidity are crucial so that their individual needs and preferences are assessed and their current and future care can be discussed and planned for. Such developments will need further research into the epidemiology of advanced multimorbidity and how to support people to 'live well' with inherent uncertainty while planning for inevitable future deteriorations in health. Many, but not all,

patients prioritise quality of life over life-prolonging treatments and usually value the chance to discuss their views and concerns about care at the end of life.<sup>38</sup>

The term 'palliative care' and its association with dying in the near future is an important barrier to patients accessing an early holistic and anticipatory approach which could improve quality of life and prevent and address psychosocial and existential distress.<sup>8</sup> Routine 'anticipatory planning' for expected deterioration in chronic illness, which can be extended in scope as the illness progresses may be more acceptable to patients and professionals. More and more of us will face many years of living with multimorbidity: the challenge is to make those years as healthy as possible.

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# BMJ Open Future Care Planning for patients approaching end-of-life with advanced heart disease: an interview study with patients, carers and healthcare professionals exploring the content, rationale and design of a randomised clinical trial

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## ABSTRACT

**Objective:** To explore the optimal content and design of a clinical trial of an end-of-life intervention for advanced heart disease with patients, carers and healthcare professionals.

**Design:** Qualitative interview and focus group study.

**Setting:** Community and hospital-based focus groups and interviews.

**Participants:** Stable community-dwelling patients, informal carers (PC, n=15) and primary and secondary care based healthcare professionals (HCP, n=11).

**Results:** PC highlighted fragmentation of services and difficulty in accessing specialist care as key barriers to good care. They felt that time for discussion with HCP was inadequate within current National Health Service (NHS) healthcare systems. HCP highlighted uncertainty of prognosis, explaining mortality risk to patients and switching from curative to palliative approaches as key challenges. Patient selection, nature of the intervention and relevance of trial outcomes were identified by HCP as key challenges in the design of a clinical trial.

**Conclusions:** PC and HCP expressed a number of concerns relevant to the nature and content of an end-of-life intervention for patients with advanced heart disease. The findings of this study are being used to support a phase II randomised clinical trial of Future Care Planning in advanced heart disease.

## INTRODUCTION

Patients with cancer have well-developed palliative care services while patients with advanced heart disease do not as highlighted in two major reports by The Department of Health in England and Wales<sup>1</sup> and Scottish Government Action Plan 'Living and Dying

## Strengths and limitations of this study

- This qualitative interview study has provided a 360° perspective from patients, carers and healthcare professionals on the content, nature and mode of delivery of an intervention that could be tested in a clinical trial and that could impact on quality of life.
- The findings suggest that a randomised (early vs delayed) protocol is broadly acceptable, that clinical prognostic scores could be used to identify eligible patients in the hospital setting, that care needs should also be incorporated into the eligibility criteria and that the intervention should include components that address the current gaps in high-quality holistic care (as identified by patients and their carers).
- The relatively small number of patients and healthcare professionals participating in the study and the fact that all patients were stable in a community setting may have impacted on the findings.
- Engaging patients and carers in the rationale, content and design of a randomised clinical trial is challenging and requires careful design and planning.

Well'.<sup>2</sup> These documents promote the provision of care in the last year of life that is person-centred regardless of diagnosis. The recent National Health Service (NHS) quality Improvement Scotland Clinical Standards for Heart Disease recommend a palliative care assessment in all forms of advanced heart disease.<sup>3</sup> Recent publications relating to end-of-life (EOL) care in heart disease have focused on congestive heart





failure (CHF) but coronary disease and valvular heart disease commonly coexist in patients with CHF, so an integrated approach to all end-stage heart diseases is appropriate.

We recently explored ways of identifying patients who are approaching EOL in an acute cardiology ward. Using the Gold Standards Framework criteria and validated prognostic tools we demonstrated that most patients with advanced heart failure<sup>4</sup> and a lesser proportion with acute coronary events<sup>5</sup> have a very limited prognosis despite optimal evidence-based care. Poor prognosis is a marker of lower quality of life, increased hospitalisation, multimorbidity<sup>6</sup> and is an indirect marker of increasing patient needs. There are well-validated prognostic tools for patients with CHF<sup>7</sup> and acute coronary syndrome (ACS).<sup>8</sup> Once a patient with a poor prognosis is identified, this should ideally be followed by an evidence-based intervention<sup>9–11</sup> that could improve quality of life for the patient and their family. In keeping with palliative care models,<sup>12</sup> this intervention should be patient-focused and should address individual needs. Ideally the intervention should integrate patient preferences with clinical priorities using 'shared decision-making'.<sup>13</sup> From these discussions, a Future Care Plan (FCP) may be derived and written in terms that the patient understands. The FCP should contain a clinical plan of how to manage acute events of deteriorating health with mechanisms to inform out-of-hours services and maintain continuity of care. The plan should be reviewed regularly in the context of the patient's evolving multidimensional needs. Such an intervention could be initiated by the patient's cardiologist and delivered by a specialist heart disease nurse working in partnership with the primary care team and palliative care specialists.

Trials of palliative care are recognised to be extremely difficult to design and implement.<sup>14</sup> One previous randomised trial suggested that routine palliative care in addition to normal oncological care could improve quality of life in people with lung cancer.<sup>12</sup> A robust phase II trial, as recommended by the Medical Research Council in its guidance for complex interventions,<sup>15</sup> is needed as a first step towards achieving a similar goal for people with advanced heart disease.

The proposed study outlined here incorporates these issues using a mixed methods, phase I and II trials, design and is similar to methodologies used elsewhere to develop complex palliative care interventions for non-cancer illnesses.<sup>16–17</sup> The proposed trial is novel in that it includes a broad group of patients with CHF and ACS; it will assess whether well-validated clinical prognostic tools can be used to identify patients approaching EOL and will develop a feasible care planning intervention. In addition to assessing prognosis as a trigger, the study also seeks to explore the interface between acute cardiology services, primary care and specialist palliative care services.

Here we describe the findings of a qualitative interview study using patient-carer focus groups (PCFG) and a

range of healthcare professionals (HCPs) to explore ways in which a holistic intervention could be tested in a randomised clinical trial setting.

## METHODS

The basic design for a clinical trial outline was developed by the authors as part of a submission for research funding using their background knowledge and experience and based on other trial designs of a similar nature.<sup>16–17</sup> This was approved by the funder and by the local ethics committee on the understanding that the design of the study could be modified following a consultation/modelling phase which would involve focus groups of patients and carers and one-to-one interviews with a range of HCPs about the proposed trial design. PCFG were then undertaken with the members of an existing hospital-based heart failure patient-carer forum (n=7) and a second focus group was undertaken in conjunction with a local heart disease charity (n=8 participants) each lasting for 2 h. Discussions were facilitated by an experienced qualitative researcher (GH) using a set of questions, designed by the authors, addressing their experiences with clinical care and the proposed design of the randomised controlled trial (see online supplementary appendix 1A). Various options associated with the trial were presented and discussed with patients and carers including eligibility criteria and whether the control group should or should not receive EOL intervention.

A separate series of one-to-one interviews were conducted with a range of HCPs (total n=11, palliative care consultant n=3, cardiology consultant n=3, heart failure specialist nurse n=1, medicine of the elderly specialist n=1, cardiology ward charge nurse n=1, general practitioner n=1, district nurse n=1) by an experienced qualitative researcher using a set of questions incorporating themes related to clinical care, palliative care and clinical trials design (see online supplementary appendix 1B).

Discussions regarding the proposed design of the trial were initially broad and later in the interview focused more on the eligibility criteria, types of patients that should be included and whether an active control group should be incorporated. Both types of participants were provided with a sample 'FCP' and a flow diagram of the basic proposed design of the clinical trial prior to the interviews. These documents acted as focal points for discussion. Interviews and focus groups were transcribed and analysed using NVivo to extract themes related to the rationale and design of a clinical trial of a holistic intervention addressing a range of issues related to EOL care.

The findings from these interviews and focus group discussions were then used to modify the proposed design of a trial of an intervention to support patients with advanced heart disease identified as being at high risk of death within the next 12 months. All participants gave signed informed consent.

## RESULTS

### Patient's and carer's views

#### Care for cardiac patients

PCFG highlighted increasing difficulties associated with multiple care providers working in apparent isolation as a major difficulty in ensuring holistic care. From a PCFG perspective, care appears increasingly fragmented and ill designed to manage the needs of frail, elderly patients with multiple chronic conditions.

PCFG also identified the variation in access to specialist services as a key problem in providing holistic, patient-centred care. This applied in particular to heart failure nurse care where many services adhere to strict eligibility criteria which include left ventricular systolic dysfunction and recent hospital admission. Patients with access to the heart failure specialist nurse service were very appreciative of their support, but they expressed concern that this service was not available to everyone with heart failure and people with other types of advanced heart conditions.

PCFG welcomed the idea of future or anticipatory care planning, and appeared to recognise its value. However, a minority felt that this could be a very difficult process to engage in, expressing views that it needs to be carefully targeted and people should be able to choose, without pressure, not to engage in the process (box 1). PCFG highlighted the fact that some patients will already be well informed about their condition and its prognosis. However, it was also expressed that for those who have less insight into their condition, doctors and nurses should consider carefully how they will allay and minimise fears about engaging in a process of Future Care Planning.

#### Box 1 Patient-carer views: fragmentation of care

Once you get to our age, you discover that you've got more than one problem, and you see the various consultants who deal with the various problems, and they deal with you like a car. They put the carburettor right, they put the radiator right, but the holistic approach is missing (patient)

My condition is primarily a chronic lung condition but I also have a heart condition. So I have two separate areas of contact and they both know about each of the conditions but they're really only concentrating on the one they're dealing with, they soon forget, 'oh, you've got a heart condition, oh right!' And it's worrying particularly if you're being administered fairly serious medication and you've got to remember that you've got all these conditions (patient)

#### Variation in access to specialist services

We have a very good rapport and have chats with her (The Heart Failure Nurse). If there's something we don't understand, she's very good at explaining what's involved, so we're very happy (patient)

Having a nurse, it gives you a bit more confidence because you just know she's there. Everyone should have one, because it does make a heck of a difference (patient)

#### Proposed trial of Future Care Planning

There was a general consensus in the PCFG that the draft FCP planned for use in the trial (see online supplementary appendix 2) was comprehensive and addressed a number of concerns that families had about planning for the future (box 2). However, one carer made the point that a patient-centred anticipatory care plan must be flexible enough to accommodate those who are acting on behalf of their loved one possibly using power of attorney. Others suggested that it would be helpful to ensure that all contact details of the medical teams caring for a patient are included particularly for those with multiple comorbidities. One patient also questioned the appropriateness of asking patients to identify which potentially life-saving treatments they may or may not want.

PCFG were supportive of the proposal for a clinical trial and were satisfied with the basic design of the study. Opposing views about eligibility criteria were expressed by two participants in the same focus group with one indicating that eligibility should include people with advanced heart disease who were currently stable in the community and not necessarily those recently admitted to hospital. PCFG emphasised the need for families to be well informed and prepared before being approached about a trial testing the proposed intervention. Eligibility for the trial using a threshold value for estimated 12-month mortality was debated and discussed

#### Box 2 Patient-carer views: draft patient-held Future Care Plan (see appendix 2 "My Thinking Ahead Plan")

I have thought about all the questions (in the proposed patient-held Future Care Plan), and I think it's very, very good. Even for yourself to write down your thoughts and wishes. Everybody's wishes are different so therefore, if it's all written down and you've got this plan, I think, yes, it's very useful for the future (patient)

...personally, ignorance is bliss in some cases (patient)

What would worry me slightly about this, especially if you're filling it out on your own (Future Care Plan), is that suddenly an end, shall we say, opens up, the fact that you're filling in something that's to do with palliative care—ooh, a horrible word—I don't know if people with heart failure are taken through this before this or do they need to be sitting with a doctor or nurse who can take them through the fact that it's not as bad as it sounds. That would worry me...getting something like this and filling it in isolation, it's frightening (patient)

Well, if you follow all the questions, really I don't think you miss much at all. Because you're asking what people are interested in and what things they do at the moment and what they hope to continue, and in a way, I think that's very good for the professionals looking after us to know that—whether in fact you're doing anything or if you're doing nothing with your life, because I think it makes a big difference (patient)



and a value of 20% was reached as one which would include a set of patients with a significantly higher than average mortality risk for cardiac patients. One further aspect of the final design of the trial which was discussed and agreed by the PCFG was whether to have a control group with no intervention or whether to have a group of patients where an intervention was provided but 12 weeks after discharge. It was generally agreed that it would be unethical not to provide an intervention of some sort to all patients who agreed to take part and so a delayed intervention group design was finally agreed (see figure 1).

### Views of HCPs

#### EOL care for patients with heart disease

Irrespective of role, all HCPs who were interviewed identified the issue of managing the uncertainty of prognosis in people with advanced heart disease as a major challenge. Most agreed that prognostic uncertainty can cause HCP to prevaricate because they are worried about 'getting it wrong' (see box 3). They also expressed concerns that discussions about EOL could remove hope for the patient and their family.

#### Proposed trial of Future Care Planning

Several HCP participants drew a distinction between different types of patients with advanced heart disease and wanted more clarity about what type of patient would be eligible for the proposed trial. One cardiologist's view was that it would be relatively straightforward to recruit patients with coronary disease although it would be more complex to identify patients with heart failure since it is hard to pinpoint at which point in their illness

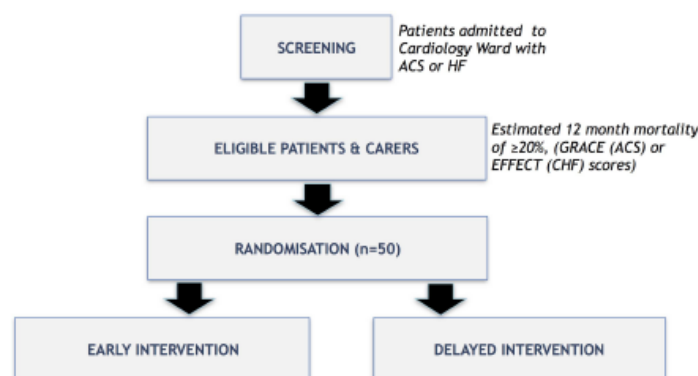
trajectory they would become eligible (see box 4). For this group, one cardiologist suggested it may be useful to use repeated hospital admissions or functional status as a criterion for eligibility.

Care of the elderly physicians raised concerns about including patients in the trial with multimorbidity including those with cognitive impairment. Such patients are typically seen in acute medical takes and while they would be a group who may benefit considerably from Future Care Planning, they would be difficult to assess, recruit and retain in the proposed trial. However, this HCP stated that to omit these patients would be unfair and could miss a key opportunity.

There were no significant concerns raised with regard to using a clinical prognostic tool, such as the GRACE score, as a way of identifying patients for a palliative care intervention. However, it was highlighted by a number of HCPs that this approach has significant limitations and using such a tool in isolation may exclude many patients who could benefit from a Future Care Planning approach who have a high level of need and a low estimated 12-month mortality risk. In addition, it was highlighted that prognostic scores do not predict time to death nor do they accurately identify those who may benefit from a palliative care intervention.

Without exception, the HCPs we interviewed had no ethical concerns with a design utilising an early versus late intervention which they regarded as a standard approach for a trial (see figure 1).

Achieving and maintaining staff engagement and thinking ahead to what happens at the end of the trial were identified as important issues. In particular, HCPs identified the importance of keeping staff informed



**Figure 1** Adapted protocol for a randomised trial of Future Care Planning for patients with advanced heart disease: original flow diagram did not define the types of patients to be included, the threshold mortality risk for eligibility and the control group intervention. This final and agreed version identifies patients admitted to an acute cardiology ward with either acute coronary syndrome or heart failure and will be screened for eligibility—12-month mortality risk of 20% or greater at the time of discharge using the GRACE discharge score<sup>6</sup> or the EFFECT score.<sup>7</sup> Eligible patients need to survive to discharge and have capacity to consent for the study. Informal carers will also participate where identified by the patient. Proposed outcomes include quality of life assessed by questionnaire (EuroQoL-5D) and readmissions to hospital. Patients randomised to early intervention will be interviewed prior to discharge and those randomised to delayed intervention will receive the same interview 12 weeks following discharge. ACS, acute coronary syndrome; CHF, congestive heart failure; HF, heart failure.

**Box 3 Healthcare professional's views: prognostic uncertainty**

...it's hard for health professionals to know where they (patients) are in their disease process, because we know they go up and down and they probably never come right back up to where they were the last time, but they're still functioning, and...at what point do you have that conversation? (District Nurse)

A lot of health professionals because of the trajectory of the disease and the up and down nature of it, nobody knows when the point of true palliation should kick in and people are very frightened because with some antibiotics or some steroids they could bounce back, not to the same state of health, each time declining and getting less well, but still not at the point where you would be comfortable saying, right, we're at the point of pure palliation (Palliative Care Consultant)

we've all seen patients who survive against the odds for a long time—if they outlive your expectations, that's OK... you might get the timing a bit wrong because you can't predict, but usually you are right that the decline has started (Heart Failure Specialist Nurse)

You don't want your patients to become obsessed and totally focused on their disease—(they've) got to get on with life as well (Medicine of the Elderly Consultant)

**Healthcare professional's views: risk of dying from a long-term condition**

"I don't think they see it, to the same extent as cancer patients—COPD patients as well. They (patients) see it as a limiting condition, it stops them doing things, it's not foremost in their mind that this is the thing they're going to die of" (District Nurse)

"Sometimes I think when it gets to the stage that you're doing DNAR forms...it often comes as a big shock to either them or their family...it comes as a shock when they're told, 'we think this is it this time', because they've been in and out, bounced back and forward, got better, gone home" (Community Palliative Care Nurse)

about the trial, consideration of how the trial might dovetail with existing service developments and the importance of providing ongoing support beyond the trial period to participants who continue to require additional supportive care.

Hospital bed-days utilisation during follow-up was generally considered to be an appropriate outcome, although several expressed caution in interpreting what these data actually mean. Quality of life measures were also considered to be an appropriate outcome, although it was pointed out that these measures can also be difficult to interpret in this setting. Some HCPs suggested the inclusion of place of death and preference for place of death as outcome measures.

The initial study design of the clinical trial did not strictly define the types of patients that could be included, the eligibility criteria, the threshold mortality

**Box 4 Healthcare professional's views: proposed trial of Future Care Planning****Patient selection for the trial:**

One group is those with advanced heart failure for whom we already have some structure to post-discharge care through our HF nurse service and the second group...are those with end stage coronary disease, so these are patients with angina for whom there's not an awful lot more can be done for them by way of bypass surgery and invasive treatments, and where these patients are intermittently hospitalised when their angina reaches crisis point (Consultant Cardiologist)

A score based on a patient's functional status is useful because it identifies when quality of life is impaired to the extent that the patient needs more support (Consultant Cardiologist)

**Eligibility for the trial:**

...harder to put frail elderly patients into a protocol-driven trial because they are so different and they've got such a mix of co-morbidities and such a mix of drugs (Consultant in Medicine of the Elderly)

I think using (a cut-off of) 20% (12 month mortality risk) is fair (Community Palliative Care Nurse)

It's still pretty high. If it's less than 20% people shouldn't imminently be dying so it gives you a chance to see what effect the intervention has (Consultant Cardiologist)

...So it's about identifying the point when you can have a reasonable conversation with somebody about deterioration, and is 20% (estimated mortality risk) right...If you make it higher you'll miss some people but you'll make the discussion more real and liveable, and that's your balance (Palliative Care Consultant)

A 20% risk threshold would include lots and lots of frail elderly people. Many of them would have a 1 in 5 chance of dying within a year even without their heart failure. It's probably not an unreasonable threshold (Medicine of the Elderly Consultant)

**Trial outcome measures**

...if you're trying to prevent hospital admissions, if they're frequent fliers, then I would have thought they're the ones, the unstable ones. If you've been able to tweak something at home that prevented the admission, I suppose this is what this would do (District Nurse)

Obviously, you do have to look at bed days but ultimately they're spending more time in hospital, from their point of view...that's possibly better for them (Community Palliative Care Nurse)

...there's a subtle distinction, for example, between trying to measure differences in quality of life on a day to day basis, and measuring overall levels of comfort, security. (Medicine of the elderly consultant)

risk for inclusion and whether an intervention should be included for the control group. The final trial design (figure 1) represents a modified version taking account of the views of patients and HCPs interviewed in this





study. This fundamental design of the proposed trial was similar to the original design presented to the PCFG and the HCPs during the interviews and focus groups. There was general agreement that a broad range of acute cardiac patients should be included and agreement was reached to include heart failure (with either reduced or preserved left ventricular systolic function) and patients with any ACS. There was discussion as to whether a delayed intervention was needed in the control group. Since current clinical services provided little or no EOL intervention for such patients, a final consensus, mainly driven by comments from patients and carers, was made to offer a delayed intervention to the control group given that the intervention addressed a clear need which was patient-centred and which could provide an apparent benefit to those who participated. The final component of the design which was agreed following the PCFG and HCP interviews was the threshold at which to set the 12-month mortality used as eligibility for the trial. The authors had proposed this to be somewhere between 20% and 40% and this was discussed by both groups. The final agreement of 20% was made largely by the PCFG after lengthy discussions as to what the typical mortality risk was for patients with CCF and ACS admitted acutely to hospital.

The findings from this modelling phase are currently being used to support the implementation of a phase II randomised clinical trial of a holistic intervention (figure 2) for patients with advanced heart disease.

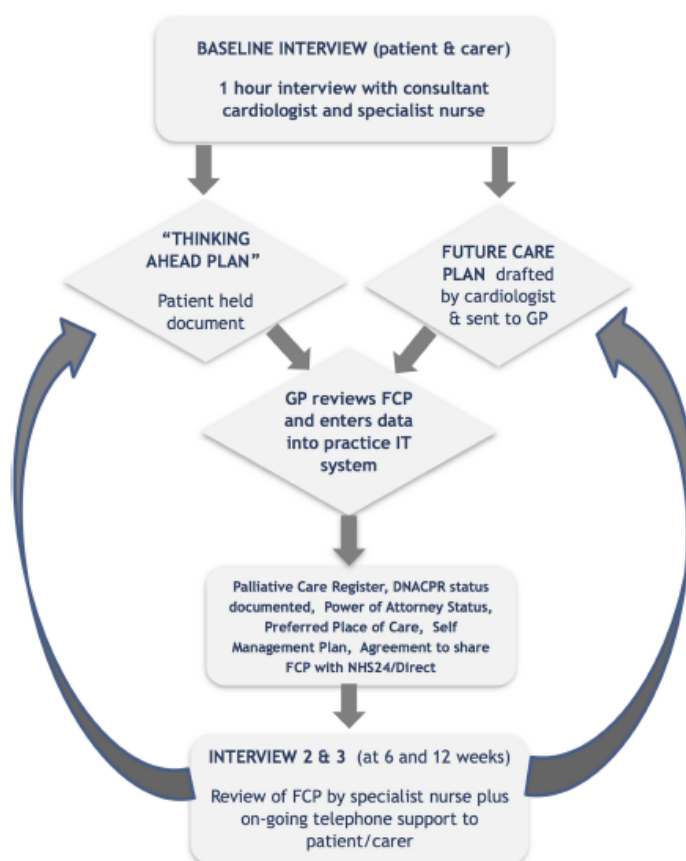
## DISCUSSION

This qualitative study examining patients', carers' and HCPs' views on the content and design of a clinical trial of Future Care Planning for patients with advanced heart disease has highlighted a number of important issues. The concerns raised by patients and carers regarding the current inadequate levels of care as cardiac patients approach EOL provide an important backdrop to the main theme of the work which was to seek their views on the content and design of a clinical trial. Patients and carers expressed views indicating that such a trial should redress the current inadequacies in a typical doctor-patient interaction which they felt had limited time and lacked a holistic approach particularly in cardiology outpatient clinic settings. The HCP participants highlighted the challenges in using meaningful selection criteria for the trial and the complexity of identifying precisely which component of any proposed intervention might influence outcomes. The findings of this work therefore reaffirm many of the findings of others in the field.<sup>18 19</sup> However, the novel aspect of the work is that the focus groups and interviews were extended beyond a general discussion stage to seek views on how the inadequacies in care could be redressed and a model developed which could be subsequently tested using a randomised trial approach.

Factors which might influence the outcomes which emerged from the PCFG discussions included the content and quality of the baseline or first discussion/interview with the consultant, the content of the written FCP and ongoing support, for patient and carer, from a familiar HCP. The views from patients, carers and professionals indicated that a clinical trial should focus on providing adequate time to discuss the patient's current and future care needs and those of their carer, it should select patients on the basis of prognosis and needs, it should provide ongoing support with primary and secondary care working closely together to ensure good coordination of care and it should allow for adaptation of any care plan in a dynamic way that is aligned with the changing needs of the patients and their carers.

While this message is clear, delivering such a trial using non-palliative care physicians in an acute cardiology environment will be challenging. Finding the appropriate language to explain an uncertain prognosis is always difficult,<sup>20</sup> and cardiologists with a firm culture of curative approaches may struggle to find that language. These challenges may delay the conversation until it is too late, or they may encourage the use of more vague, ambiguous or even contradictory language which can sometimes mislead the patient and their family or fail to communicate the seriousness of their condition adequately. Finding language that is balanced, caring and which makes sense of an uncertain future is one of the challenges of all palliative care even where the prognosis, good or bad, is more certain. However, the majority of the HCPs who we interviewed agreed that it should be possible in most cardiac patients with advanced disease. Surviving with a chronic condition that has an uncertain illness trajectory can mean that these patients, unlike patients with cancer, can reach a fairly advanced stage in their illness without realising that they have a condition that could and probably will cause their death.

Our findings have also highlighted a persisting tendency for patients and HCPs to associate palliative care with dying. This perception may prevent or discourage healthcare teams from offering palliative and supportive care to patients with significant symptom burden who may not have reached the end of their lives but who may benefit from additional supportive care. HCPs held the view that patients and carers may be reluctant to accept a form of support which they associate with EOL. This may reflect reluctance on the part of the HCPs as much as the patient. This is an important issue if we are to develop a model of integrating palliative care earlier in the illness trajectory of cardiac disease by the heart team caring for the patient. In addition to learning and developing the skills required to do this, these teams will also need to change attitudes and culture. Indeed, while this culture is increasingly acknowledged as important for patients with chronic heart failure, there is also a clear need for this approach in patients with other forms of advanced cardiac disease such as coronary and valvular heart disease.



**Figure 2** Future Care Plan (FCP) intervention: the intervention will last for 12 weeks. Patients randomised to early intervention will have a 1 h interview with a cardiologist prior to discharge where they will discuss their heart condition, other medical conditions and their concerns and plans for the future. The cardiologist, trained in Advanced Communication Skills, will aim to address a range of issues including (1) a FCP, agreed with the patient and their carer, which includes advice to healthcare professionals about what could and should be done if the patient's condition deteriorates once again, (2) whether the patient and their family have arranged Power of Attorney (or similar), (3) whether the patient wishes to consider the issue of DNACPR (Do Not Attempt Cardiopulmonary Resuscitation), (4) whether the patient wishes to express a preferred place of care should their condition deteriorate again, (5) whether the patient would consider being added to their general practitioner's (GP) Palliative Care register and (6) permission to share the content of the FCP electronically with out-of-hours medical services (NHS24/NHS Direct). Patients will also be encouraged to complete 'Thinking Ahead Plan', a locally developed patient-held anticipatory care plan (see online supplementary appendix 2). Patients randomised to delayed intervention will undergo the same interview 12 weeks after discharge. During the follow-up period of 12 weeks, the trial nurse will visit the patients/carers in their home at 6 and 12 weeks after the baseline interview in order to update the FCP with any changes and to review any DNACPR orders or make any necessary changes to the plan of care. An updated version of the FCP record will be communicated in writing to the GP at each of these time points. The nurse will be available to communicate with the patient by telephone at any time and will ensure optimal communication and coordination of care between GP, cardiologist, community-based nursing teams and palliative care teams (where appropriate).

The barriers to achieve good holistic care for patients nearing the end of their lives, well described in other settings,<sup>21 22</sup> apply equally well in the acute cardiology setting.<sup>23</sup> There is insufficient time to discuss such sensitive issues, the hospital environment is not ideal (particularly in multi-bedded rooms), cardiologists are not

adequately trained and in cardiology there is a culture of doing more and never giving up. However, particularly in elderly patients and even with optimal interventions, the combination of CHF, coronary heart disease, valvular heart disease and other non-cardiac comorbidities is associated with poor prognosis.<sup>24 25</sup> Indeed, the increasing



use of transcatheter aortic valve implantation in patients who are deemed unsuitable for conventional surgery is increasingly recognised as a clinical challenge balancing aggressive intervention with supportive EOL care.<sup>26–29</sup>

Hence, patients with advanced heart disease and poor prognosis are clearly a target for better clinical care encompassing an approach that acknowledges that the patient may be nearing the EOL. These patients rarely receive care that addresses their individual needs and those of their informal carers. This care need not be labelled as palliative but can be delivered in the understanding that the future is uncertain and the risk of death, either sudden or with progressive symptoms, is significantly increased. This need not exclude a positive attitude to the patient's clinical care and where possible the HCP should emphasise the need for ongoing active and responsive care. The challenge, and arguably the key issue, is maintaining a positive attitude while simultaneously acknowledging a poor prognosis. However, if this approach can be adopted by the patients, their family, general practitioner and cardiologist, then it can potentially improve communication and understanding in a way that leads to better care without loss of hope for the patient. Any such intervention should be patient-centred in all aspects of its design and the impact on healthcare measures must be seen as secondary to the primary aim of improving quality of life. This is challenging even in cancer care where there have been few clinical trials adequately powered to show clinically meaningful benefits using a holistic approach.<sup>12</sup> If improved clinical outcomes could be demonstrated in a clinical trial involving patients with advanced heart disease, then this would be extremely valuable to patients and the wider cardiology community.

This study has clearly demonstrated that patients, carers and HCPs have a number of concerns in relation to providing high-quality holistic care for patients with advanced heart disease. The approach reported here of seeking views on the inadequacies in service provision, designing an intervention model that could improve care and incorporating this into the design of a randomised trial is novel and important given the dearth of clinical trials in EOL care. The findings are currently being used to support implementation of a phase II randomised clinical trial of a holistic intervention involving Future Care Planning for patients with advanced heart disease.

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## C. Supportive and Palliative Care Indicators Tool



### Supportive and Palliative Care Indicators Tool (SPICT™)



**The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.**

#### Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

#### Look for any clinical indicators of one or more advanced conditions

##### Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

##### Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

##### Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

##### Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

##### Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

##### Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

##### Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

#### Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website ([www.spict.org.uk](http://www.spict.org.uk)) for information and updates.

SPICT™, April 2015